

# MARIA AFZELIUS

## FAMILIES WITH PARENTAL MENTAL ILLNESS

Supporting children in psychiatric and social services





**FAMILIES WITH PARENTAL MENTAL ILLNESS**

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# ABSTRACT

Children living with a parent with a mental illness can face difficulties. Parental mental illness may influence the parents' ability to cope with family life, where the parents' awareness of their illness plays an important role. Family interventions provided by psychiatric and children's social care services can be a way to support these children, making them feel less burdened, and improving the relationships within the family. The aim of this thesis was to illuminate how children in families with a parent with a mental illness are supported in psychiatric and social services, especially by means of family interventions, and how families experience the support.

Study I explored how professionals in adult psychiatric outpatient services deal with children and families when a parent has a mental illness. The findings showed that professionals balanced between establishing, and maintaining, a relationship with the patient and fulfilling the legal obligations towards the patient's children. Asking the patient about their children could be experienced as intrusive, and involving the patient's family in the treatment could be seen as a dilemma, in relation to the patient. Efforts were made to enhance the family perspective, and when the patient's family and children joined the treatment this required flexibility from the professional.

Study II examined how professionals in children's social care services experience working with children and families when a parent has a mental illness. The social workers' objective was to identify the needs of the children. No specific attention was paid to families with parental mental illness; they were supported in the same way as other families. When the parental mental illness became difficult to handle both for the parent and the social worker, the latter had to set the child's needs aside in order to support the parent. Interagency collaboration seemed like a successful way to support these families, but difficult to achieve.

Study III investigated if patients in psychiatric services that are also parents of underage children, are provided with child-focused interventions or involved in interagency collaboration between psychiatric and social services and child and adolescent psychiatry. The findings showed that only 12.9% of the patients registered as parents in Psykiatri Skåne had registered children under the age of 18 years. One fourth of these patients had been provided with child-focused interventions in psychiatric service, and 13% of them were involved in interagency collaboration. If a patient received child-focused interventions from the psychiatric services, the likelihood of being involved in interagency collaboration was five times greater as compared to patients receiving no child-focused intervention.

Study IV explored how parents and their underage children who were supported with family interventions experienced these interventions. The results showed that parents experiencing mental illness were eager to find support in explaining to and talking with their children about their mental illness, although the support from the psychiatric service varied. Both children and other family members appreciated being invited to family interventions. After such an intervention, they experienced the atmosphere in the family as less strained and found it easier to communicate with each other about difficulties. Unfortunately, the participating partners felt that they were left without support specifically targeted at them.

The thesis showed that there is a gap between how professionals deal with questions concerning these families and their support, and the parents' and the families' needs to receive support in handling the parental mental illness in the family. The psychiatric and social services need to expand their approach and work with the whole family, in order to meet the needs of the child and other family members involved.

## ORIGINAL PAPERS

This thesis is based on the following four studies. These studies will be referred to in the text by their Roman numerals I - IV. All papers have been reprinted with kind permission from the publishers.

I. Afzelius, M., Plantin, L., & Östman, M. (2015). How adult psychiatry professionals view children. *Austin Journal of Psychiatry and Behavioral Sciences*, 2, (2).

II. Afzelius, M., Plantin, L., & Östman, M. (2016). Children of parents with serious mental illness: the perspective of social workers. *Practice*, doi: 10/108009503153.2016.1260705

III. Afzelius, M., Östman, M., Råstam, M., & Priebe, G. Parental mental illness in adult psychiatric care: Interagency collaboration with social services and child and adolescent psychiatry. Submitted.

IV. Afzelius, M., Plantin, L., & Östman, M. Families living with parental mental illness and their experiences of family interventions. Submitted.

Maria Afzelius contributed to the above studies by initiating and designing the studies together with M.Ö. M.A. collected all data, in study I and II with support from L.P, and in study III with support from G.P. M.A. performed the analyses together with the co-authors and wrote study I, II and IV in cooperation with M.Ö., and L.P. In study III M.A. and G.P. analysed the data together and the paper was written by M.A. in cooperation with G.P and M.Ö.

# INTRODUCTION

Children of parents with mental illness have become an area of interest during the last decades both in research and in society. These children have been described as vulnerable and invisible, and in recent years the support to these children and their families has increased. In Sweden, legislation has made an increased awareness of these children's needs of information, advice, and support mandatory in health care services since 2010 (Health and Medical Services Act, SFS 2017:30, 5:7).

Parental mental illness can affect family life in many ways, since the illness itself involves symptoms that have an impact on emotions and relationships (Perera, Shorter, & Fernbacher, 2014; Venkataram & Ackerson, 2008). Children are dependent on their parents and parental mental illness can affect the parenting in a way that can jeopardize the child's health and development (Barker, Copeland, Maughan, Jaffee, & Uher, 2012; Beardslee, Gladstone, & O'Connor, 2011; Weissman et al., 2006). However, not all children suffer harmful effects (Falkov, 2012), and many parents are able to function as parents even though they have a mental illness. Children living with parental mental illness may experience constant worries for the parent, not understanding what is the matter with her or him, harbour feelings of loneliness, and take too much responsibility for the parent (Gladstone, Boydell, Seeman, & McKeever, 2011; Östman, 2008). The risk of family discord, stress, and conflicts between the child and the parent and between the parent and other family members (Venkataram & Ackerson, 2008) may increase. Parental mental illness can also be compounded with other risk factors, such as comorbidity and poverty, unemployment, and social isolation (Westad & McConnell, 2012), factors that affect the child's development and family life. Furthermore, the parent's awareness of his or her mental health,

as well as the kind of support the parent receives, may influence the parenting (Beardslee, 2002; Solantaus & Toikka, 2006; Van der Ende, Busschbach, Nicholson, Korevaar, & Weeghel, 2016).

International studies estimate that between a third and a fourth of adults treated in psychiatric services (Luciano, Nicholson, & Meara, 2014; Maybery, Reupert, Goodyear, & Crase, 2009) have children under the age of 18 years.

National studies show an almost similar pattern: one third of adults treated in psychiatric services in Sweden are parents of children under 18 years of age (Skerving, 2007; Östman & Eidevall, 2005). In order to decrease the negative outcomes for children and support parents with mental illness, several interventions for the families have been designed. However, these children have to be identified before support is introduced.

Both psychiatric services and children's social care services are welfare organisations that support families where a parent has a mental illness. Especially the psychiatric services have an important role in identifying whether their patient is also a parent of underage children (Östman & Afzelius, 2011), and in initiating child-focused interventions, when this is needed, as well as making sure that the child is not maltreated. In several countries legislation states that children of parents with mental illness have the right to be recognized and supported in health care, and this is also the case in Sweden since 2010 (Health and Medical Services Act, SFS 2017:30, 5:7). Furthermore, in Sweden, children's social care services have the responsibility to make sure that the child is growing up in a safe and stable environment (Social Services Act, SFS 2001:453, 5:1,1a) when the child's custodian fails to do so.

When services afford family interventions in cases of parental mental illness, this approach has been shown to relieve the worries the child may feel concerning the parent (Pihkala, Sandlund, & Cederström, 2011), decrease the burden on the family, improve family relationships, and reduce the parent's relapse rate (MacFarlane, 2011). International studies disclose that professionals refer to several barriers in their approach to families with parental mental illness, barriers related both to the workplace circumstances and to the families (Lauritzen, Reedtz, Van Doesum, & Martinussen, 2014; Maybery & Reupert, 2006; Tchernegovski, Reupert, & Maybery, 2017). However, how professionals in Swedish services experience their approach to parental mental illness in families is less investigated. By providing an insight into how parental mental illness is dealt with in services that usually meet these families, and by interviewing families that have experienced family interventions in psychiatric and social services, this thesis can be seen as an attempt to illuminate both the actors' and the families' view of

family interventions in parental mental illness. The knowledge resulting from this research can prove to be of value for practitioners in the area of parental mental illness.

Even if this thesis focuses both on adult psychiatric and social services, it was written from the perspective of adult psychiatric services (further on in the text referred to as psychiatric services), and the purpose was to investigate, both by means of interviews and in a register study, in what way professionals working in psychiatric services are taking children into consideration in treatment and support when a parent has a mental illness. The interview study took place in outpatient services treating mostly patients with affective mental illness. According to prevalence studies, these services have been shown to have more patients with parental mental illness (Priebe & Afzelius, 2015; Östman & Eidevall, 2005) than patients diagnosed with psychosis. The register study was conducted in a psychiatric clinic, where the medical record database was used to investigate how patients that are parents of underage children receive support concerning their children. In order to fully understand the effect of support to families and children, the thesis also tried to explore how families and children experience the support received.

Since the Swedish legislation expects a close co-operation between psychiatric services and children's social care services when there are underage children in families with parental mental illness (National Board of Health and Welfare, 2010a), another study had the purpose to investigate how professionals in children's social care services experience their work with children of mentally ill parents. The social services can be an actor of paramount importance for supporting children in families with mental illness. In this thesis, the term mental illness is used in a wide sense, covering mental illness treated in psychiatric services, and underage children are defined as children under 18 years of age.

Family is defined in a broad way, in accordance with Eggenberger and Nelms (2006) and Pilz and Gustavsdottir (1995), including the people living in the same household, such as the nuclear family with children and parents, the divorced parent and his or her relatives and the possible new partners and their relatives, and the family of origin.

Family intervention is used as an umbrella term for interventions such as family meetings, child -and parent support groups, support that families with parental mental illness can be provided with.

# BACKGROUND

## Prevalence studies

International studies trying to estimate the prevalence of patients that are parents of underage children and the number of underage children living with a parent with a mental illness, vary with regard to both methodology and results. A study from the United States (Luciano et al., 2014) estimated that 38% of mothers and 23% of fathers with a mental illness have children using data from the U.S. National Survey on Drug Use and Health. An Australian study focusing on children and families estimated that one fourth of all children in Australia had at least one parent with a mental illness (Maybery et al., 2009). In Finland, it is estimated that a fourth of the patients treated in psychiatric care are parents (Korhonen, Pietilää, & Vehviläinen-Julkunen, 2010), and in Norway, 720 randomly selected medical records in psychiatric inpatient care showed that almost a third of those selected patients had children (BarnsBeste, 2013).

Furthermore, Swedish studies concerning the prevalence of parents with mental illness – studies that in addition to the prevalence also account for the diagnosis of the parental mental illness – show almost similar results (Östman & Hansson, 2002). Östman and Eidevall's (2005) cross-sectional survey in a psychiatric service in the south of Sweden, involving 137 patients, found that a third (36%) of the patients declared that they were parents of children under the age of 18 years. One fifth of patients with children had a psychosis diagnosis, two fifths an affective disorder, and two fifths had another psychiatric disorders. In a register study from a psychiatric clinic where the care register was linked to Statistics Sweden, Skerfving (2007) found that out of 7,683 patients, approximately one third were parents of underage children. Two thirds of these patients were women. Half of the parents were diagnosed with affective disorders, one quarter of the parents were diagnosed with psychosis and addiction/personality disorders, and the rest had no diagnosis. Priebe and Afzelius (2015) investigated, in a register study of

patients in 2013 and 2014, in what way a clinical guideline concerning children's need of information, advice, and support when a parent has a mental illness, is utilized in Psykiatri Skåne, the specialist psychiatric care in the south of Sweden, Skåne. The researchers arrived at almost the same result regarding the number of patients that were registered with underage children in 2013 (12.5%) and in 2014 (12.9%), numbers in opposition to other national data. The number of patients with registered children was greater among women than men in both years. In 2013, patients with a main diagnosis of substance abuse, mood disorders, and neurotic stress disorders, were more likely to have registered children, in comparison with 2014, where patients with a main diagnosis of behavioural and emotional disorders, and neurotic stress disorders, were more likely to have registered children.

In another Swedish study, Hjern and Manhica (2013) investigated how many children are relatives of parents with a mental illness, a severe somatic illness, or substance abuse, or of parents that were victims of sudden death. They analysed linked inpatient data from the Patient register during 1987 – 2008, and the Death register during 1973 – 2008. Among the children born between 1987 and 1989, 5.7 % had a parent that had been treated in inpatient care for a mental illness.

### **Parenting and mental illness**

Studies concerning mental illness and parenting focus mostly on the mothers' experiences, and in studies with both mothers and fathers, mothers are in a majority, since women with mental illness are more likely to have children (Diaz-Caneja & Johnson, 2004) and are often the primary caregiver of the child/children (Skerfving, 2007; Östman & Eidevall, 2005). Further, the parenting domain by tradition belongs to mothers (Price-Robertson, Reupert, & Maybery, 2015). Spector (2006) notes that paternal depression can be difficult to identify, since fathers tend to withdraw from social situations, have problems making decisions, and exhibit an irritable mood. However, the recognition of fathers with mental illness has gained attention in recent years due to a more equality-based view of parenting in society (Styron, Kline Pruett, McMahon, & Davidson, 2002).

Several studies highlight parents' needs of support in raising their children, as well as the need of support for their children so that they can achieve an understanding of their parent's mental illness (Evenson, Rhodes, Feigenbaum, & Solly, 2008; Van der Ende et al., 2016). There is, however, sometimes a conflict between those needs and the parents' fear of losing custody of their children because of their mental illness (Bassett, Lampe, & Lloyd, 1999; Diaz-Caneja & Johnson, 2004; Price-Robertson et al., 2015; Rampou, Havenga, & Madumo,



2015; Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003). Furthermore, feelings of being stigmatized are common (Bournell, 2007; Cremers, Cogan, & Twamley, 2014; Rampou et al., 2015; Wilson & Crowe, 2009), as well as a fear of being judged as not being good enough parents.

Mothers with bipolar disorder spoke of being stressed and feeling incompetent as a mother (Newman, Stevenson, Bergman, & Boyce, 2007). The impact of the mental illness sometimes made parenting a burden, and parents expressed difficulties in monitoring their own emotions in relation to parenting (Venkataraman & Ackerson, 2008; Wilson & Crowe, 2009). Narratives by mentally ill parents describe a depressive phase that made the parent lose energy and stay in bed, a situation inducing suicidal thoughts, succeeded by a manic phase characterised by over-activity and being wrapped up in oneself, but also by helpfulness, since this phase raised the parent's energy levels (Venkataraman & Ackerson, 2008). Furthermore, studies describing how parents relate to their children, show that parents often felt tired, having difficulties in motivating themselves, which contributed to a low interaction with their children, and that one of the side effects of the medication was having trouble to concentrate (Evenson et al., 2008; Rampou et al., 2015). Nevertheless, several parents in the studies talked about how important their children were to them and how they strived to be a good parent (Bassett et al., 1999; Diaz-Caneja & Johnson, 2004; Evenson et al., 2008; Perera et al., 2014; Savvidou et al., 2003). They were stressed by the fact that when they, for example, needed to seek psychiatric care, they did not know how to handle the situation of the children (Evenson et al., 2008). Several of the parents were single, without support in their everyday life (Bassett et al., 1999; Diaz-Caneja & Johnson, 2004; Saavidou et al., 2003; Skärsäter, 2006). Some parents also worried that their children would inherit their illness (Diaz-Caneja & Johnson, 2004; Evenson et al., 2008; Skärsäter, 2006).

### **Children and parental mental illness**

Children in families with parental mental illness may experience more problems than other children without a parent with mental illness, problems such as difficulties with attachment, the risk of developing a mental illness of their own, a high risk of stress reactivity, school failures, and other problems connected to living in a high-conflict family (Beardslee, Versage, & Gladstone, 1998; Beardslee et al., 2011; Hosman, van Doesum, & van Santvoort, 2009; Reupert, Maybery, & Kowalenko, 2012; Rutter & Quinton, 1984). Longitudinal studies concerning the outcomes for children with a parent with an affective mental illness show a greater risk for those children to develop a mental illness compared to children of healthy

parents (Beardslee et al., 1998; Beardslee et al., 2011). Weissman et al. (2006) found that the risk for children of depressed parents to develop depression was three times as high as for children with non-depressed parents. Children of parents with schizophrenia are found to have an increased risk of developing schizophrenia but also other mental illnesses (Dean et al., 2010). Studies concerning the transmission of parental mental illness to offspring show a broad range of adverse outcomes in children, including the same mental illness as the parent (van Santvoort, van Doesum, & Reupert, 2015).

Not only genetic but also environmental factors can have an impact on the child's health and development (Beardslee et al., 1998). The parents' potentially deficient ability to parent when having a mental illness can be considered a risk for the child (Oyserman, Mowbray, Allen Meares, & Firminger, 2000), just as the chronicity and severity of the parental mental illness. Having two parents with mental illness can also affect the child's well-being negatively (Beardslee et al., 2011). Other psychosocial factors, such as separations, marital conflicts, violence (Hosman et al., 2009; Rutter & Quinton, 1984), and single parenting, can affect the child and his or her health. Furthermore, the caring responsibility the child can have for their mentally ill parent, especially in single-parent families, may have an impact on the child's well-being (Aldrige & Becker, 2003).

When children of mentally ill parents are interviewed about how they experience their lives with parental mental illness, they reveal that they seldom know about their parent's mental illness and have difficulties in understanding it (Gladstone et al., 2011). Family life can be experienced as unpredictable and unsafe when the parent's mood suddenly changes (Dam & Hall, 2016; Gladstone et al., 2011; Trondsen, 2012), which makes the children constantly observant of the parent's mood (Hedman Ahlström, Skärsäter, & Danielsson, 2011). When conflicts appear in the home, some children withdraw to their rooms in order to seek solitude (Dam & Hall, 2016; Fjone, Yttervik, & Almvik, 2009), while others try to support and comfort the parent (Dam & Hall, 2016). These children often feel lonely and without support (Östman, 2008), and the lack of understanding regarding why the parent is not emotionally available can make them feel guilty of having done something that the parent dislikes (Hedman Ahlström et al., 2011). They worry that the parent will get worse or that the parent will attempt to commit suicide (Dam & Hall, 2016), thoughts that scare them, and in some cases this makes the children stop going to school, taking part in activities, or being with their peers, because they have to take care of their parent (Gladstone et al., 2011). Some children hide the parental mental illness in order not to feel ashamed of their parent (Dam & Hall, 2016; Fjone et al., 2009). Furthermore,

children sometimes take a large responsibility for the household and for their siblings (Dam & Hall, 2016; Gladstone et al., 2011).

Adult children reveal how having grown up with a mentally ill parent influences their lives even though they do not live together with the parent any more (Murphy, Peters, Jackson, & Wilkes, 2011). Some adults express a difficulty in establishing and maintaining trustful relationships, and a need to grieve their childhood with a parent that was not always emotionally available. As in the younger children's experience, the adult children also recalled the ongoing worries they had for their parents (Mechling, 2016). A feeling of hope that things would become better functioned as a protective factor, however.

Studies of children's experiences of living with a parent with a mental illness also entail the children's perception of their own strengths in coping with the parental mental illness. A review by Drost, van der Krieke, Sytema, and Schippers (2016) found that these children described themselves as having gained several abilities, such as being more creative, more empathetic, and more mature, in comparison with their peers.

### **Support given to families with parental mental illness**

The support to families with mental illness can be reflected upon from various perspectives. One such perspective is how different theories about the treatment of mental illness are applied in a clinical context, as well as how societal movements have influenced this treatment. In the early days, the family was almost the only existing support for a person with a mental illness. This state of affairs was followed, all over the Western world, by the institutional era, where persons with mental illness were taken out of their family and isolated, in order to recover (Ottoson, 2003; Åsberg & Agerberg, 2009).

At the end of the 19<sup>th</sup> century, support, if any, to families with mental illness was in social services based on family casework (Montalvo, 1982) aiming to help families cope with poverty and misery. Social problems were viewed as moral problems in need of being controlled. Later on, during the 20<sup>th</sup> century, family casework developed from viewing poverty as a moral problem to focusing on how external factors could influence the family life (Pettersson, 2001). The first child protecting law was established in Sweden in 1902 (Hamreby, 2004). Children in families where the parents were considered negligent or where the family lived in poor environments, were placed in an orphanage. Further, in 1935, women with intellectual disabilities were sterilized in order to prevent them from reproducing. In the 1950s, the Children's Village Skå (Barnbyn Skå, in Swedish) was established, and a new approach was introduced, with

treatment organised in such a way that both the child and the surrounding family were taken into consideration (Hamreby, 2004). Nowadays, the social care for families and children is often organised in specialized teams or groups, where social workers assess and investigate applications from families and referrals from welfare organisations (Bergmark & Lundström, 2008). The Swedish child welfare is based on the idea of child maltreatment as a problem due to family dysfunction, which means that the whole family needs to be supported by help and interventions (Svärd, 2016; Wiklund, 2008). Family work in children's social care services today offers several different interventions for families, and the umbrella term family intervention can involve family therapy, family meetings, interaction guidance methods, social network therapy, and home-based family work, for vulnerable families in need of support (Löwenborg & Sjöblom, 2009).

Also the psychiatric services were influenced by societal changes, and as the deinstitutionalization of the treatment of mental illness was performed and outpatient clinics were established, the community-based service had to be developed in order to care for families with mental illness (Östman, 2000). The families now also gained a new role as caregivers for the mentally ill person. With improved medical treatment, mentally ill persons could manage their mental illness outside hospitals, which increased their possibilities for starting families and raising children (Oyserman et al., 2000).

Freud and his psychoanalytic theory constituted the main influence on the psychological treatments provided during the 20<sup>th</sup> century (Lundsbye, Sandell, Ferm, Währborg, & Petitt, 1983). However, several sciences started to pay more attention to the social context, and to the interaction between individuals (Lundsbye et al., 1983). The family therapy movement grew as a result of an interest in system theory. In system theory, instead of viewing the problem as situated within the person, as in the individual therapy approach, the problems are understood as part of the family system in which each family member's actions affect the system and each member's responses to those actions affect the whole family's balance and functioning (Härtveit & Jensen, 2007).

Applying the family perspective to the support of children living with parental mental illness has been beneficial, for both parents and children. The parents receive support in parenting, as well as information about risk and protective factors concerning their children, and a dialogue, aimed at opening up the communication about the parental mental illness in the family, is facilitated (Beardslee, 2002). Education concerning the mental illness is an important component in interventions, since both parents and children have requested information about the parental mental illness, in order to reduce

the misconceptions about it in the family (Reupert & Maybery, 2010). Family interventions can also strengthen the resilience in the family, which can contribute to enhance the communication in the family and improve the atmosphere (Power et al, 2016; Walsh, 2006). Furthermore, family interventions have been shown to be effective in decreasing the risk of children getting their own mental illness, as found in a review by Siegenthaler, Munder, and Egger (2012, and several family intervention programmes have been developed internationally, for example in Australia (Steer, Reupert, & Maybery, 2011), the Netherlands (Hosman et al., 2009), the United Kingdom (Falkov, 2012), and the United States (Nicholson, Hinden, Biebel, Henry, & Katz-Leavy, 2007) in order to reduce negative outcomes in children. Family intervention includes a range of strategies and methods, although not always involving the whole family. Various programmes for the children have been developed, such as peer support programmes or child support programmes (Grové, Reupert, & Maybery, 2015; Van Santvoort, Hosman, van Doesum, & Janssens, 2014), and online interventions (Drost & Schippers, 2015; Trondsen & Tjora, 2014). Those programmes and interventions have been shown to make the children seek more social support, as well as improving their knowledge of mental health issues. Support can also be provided to parents in parental support groups (Reupert & Maybery, 2011; Shor, Kalivatz, Amir, Aldor, & Lipot, 2015), aimed at strengthening the parenting skills and supporting parents in their ability to overcome barriers in seeking help from the support systems related to their children.

### **Contemporary legislation**

The growing awareness of the situation of children living with parental mental illness has been the subject of governmental initiatives and policies concerning the recognition of and support to these children in several countries.

Legislation concerning the responsibility of the psychiatric services to recognize children of mentally ill parents has been introduced in countries such as Norway (Lauritzen et al., 2014), Finland (Solantaus & Toikka, 2006), and Australia (in Victoria) (Tchernegovski et. al., 2017).

In Sweden, the Mental Health Reform (National Board of Health and Welfare, 1999) with the intention to normalize the living conditions for persons with mental illness, put forward the need for relatives to be included and supported in the rehabilitation of the mentally ill person. At the same time, the Child Psychiatric Committee, aimed at investigating the care of, and the support to, children with mental ill health, was initiated by the government (SOU 1998:31). The committee stated that the psychiatric services have a responsibility to inform

themselves about the situation of children of parents with a mental illness, and those children's need of information and support, and proposed this as an addition in the Health and Medical Services Act (SFS 1982:763)<sup>1</sup>. The investigation also highlighted the need for psychiatric services to support the patient's parenting.

Furthermore, the National Psychiatry Coordinator, appointed by the government in 2003, stated in his final report (SOU 2006:100) that relatives of persons with a mental illness should be more recognized, by means of routines for information to, and support of, the social network around the patient, and by means of evidence-based family interventions. The report also emphasized the need for routine support to the children of a person with a mental illness, as well as the fact that the psychiatric services and the primary health care have important roles in identifying these children and initiating support. This approach requires child- and family-oriented work, and collaboration between psychiatric services, school, primary health care, child and adolescent psychiatry, and social services. The investigation proposed that the government should follow the development concerning these children, and consider a clarification, according to the Child Psychiatric Committee's suggestion, in the Health and Medical Services Act (SFS 1982:763), if needed.

The National Psychiatry Coordinator also performed a survey of all psychiatric services in Sweden, asking them about the support and collaboration provided for children and parents at the clinic. Half of the clinics answered that they had routines for how to approach children of parents with a mental illness such as support sessions and child support groups. Furthermore, half of the clinics had routines for children when a parent had committed suicide. Only one third of the clinics had a specific method for supporting these children, however. About 80% of the clinics said that they had a good collaboration with the social services. Finally, almost 90% of the clinics said that there was something lacking regarding the choice of aid in supporting the children.

The Swedish government decided, in accordance with the National Psychiatry Coordinator's advice, to clarify the legislation concerning the needs of these children, and additions were made in the Health and Medical Services Act (SFS 1982: 763, 2g). The act states that children's needs of information, advice, and support shall be taken into account by health care professionals if the child's parent, or any other adult individual that the child is living permanently with, has a mental illness or a serious physical disease or injury, and in case of parental addiction or sudden parental death. According to the National Board of Health and Welfare (2010b), it is important that the child is able and allowed to express his or her own opinion and need for support, depending, however, on the age

1 The former term of the Health and Medical Services Act (SFS 1982:763) is used in this section.

and maturity of the child. As for children with a parent with a mental illness, a national project was initiated to educate professionals in psychiatric services and primary health care in Beardslee's family intervention (Ministry of Health and Social Affairs, 2006).

The Swedish Parliament ratified the UN Convention on the Rights of the Child in 1990, and is obliged to follow the decisions in the convention. The government bill "Strategy to strengthen the rights of the child" in Sweden (SOU 2009/10:232) is supposed to make sure that organisations in municipalities and regions are able to ensure that the conventions are realized. In 2013, The National Board of Health and Welfare (2013), advocated the importance of taking a family perspective in health care when meeting parents with a mental illness, and of broadening the possibility to receive care adapted to the individual needs of the child, parents, and families, as well as developing a collaboration with other services in order to address those needs.

### **Rationale for this thesis**

Recent research has shown that supporting the family around the person with a mental illness, and especially the underage children, is of great importance for the development and well-being of the child (Beardslee et al, 2011; Foster, O'Brien, & Korhonen, 2012; Hosman et al., 2009; Reupert et al., 2012). Research in family intervention and parenthood has until now been focused on finding evidence-based methods for support (Beardslee, 2002; Solantaus & Toikka, 2006), and there is limited knowledge concerning the experiences of those families given the support in a natural clinical context (Schrank, Moran, Borghi, & Priebe, 2015).

Further, the research has mainly focused on mothers' experience of parental mental illness in family life, while the fathers' voices have been more silent. Finally, how family interventions are experienced by the families themselves can provide valuable knowledge to both professionals and the society concerning how to support these families, and may have further implications for the clinical family work.

# THEORETICAL FRAMEWORK

The ecology of human development perspective (Bronfenbrenner, 1979) may be suitable in creating an understanding of children living in families with parental mental illness and their possibilities for being supported, with the aim of improving their well-being. In order to understand children and their development, Bronfenbrenner believed that one has to take into account both the children and their environment and how these two interact with each other.

Children, like all human beings, live in a social context. In this social context there is a mutual interaction between the children's ongoing development and the changing environments they live in. This can be viewed as a model constructed by subsystems whose structures are influenced by each other. The model includes all the systems in which a child is embedded, and, because it reflects the connections between other systems and the child, it can provide a holistic perspective with regard to understanding what circumstances children in families with parental mental illness live in and how they can be supported.

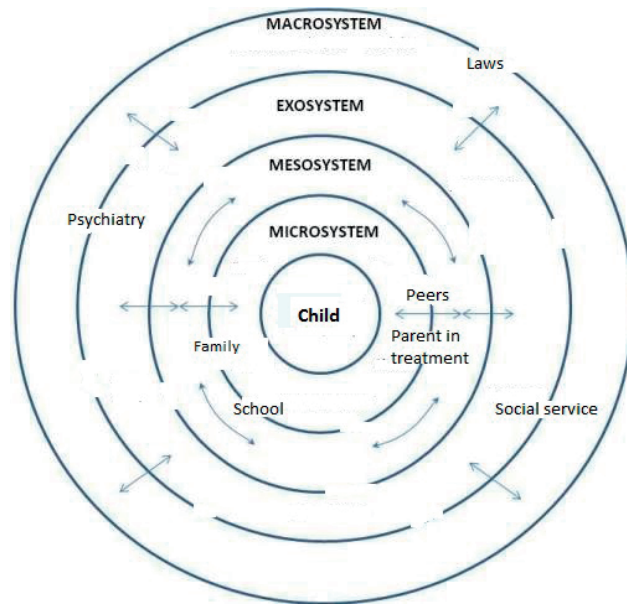
The family is usually the most intimate microsystem for these children. In the microsystem, the child learns how to live and build trustful relationships. When parents are overwhelmed by their mental illness, it can influence the interaction with the child and the ability to be sensitive to the child's needs. According to Bronfenbrenner, the child belongs to several microsystems, such as day care, school, and peer groups. Other microsystems that can have an impact on the child are those that are part of the parent's own support system, for example the parent's close relationship to his or her psychotherapeutic contact.

The mesosystem, the system that involves the relations between different microsystems, can be very important for the child's well-being, especially when the different microsystems that may be helpful for the child can connect between each other and provide support or caring for the child and the family.



The third system is the exosystem, that is, the system that the child may not belong to but can be affected by, like the psychiatric or social services in which the parent is a patient or client, and other contexts and resources on this level.

The macrosystem, finally, affects all persons in society; it includes the political, social, economic, and cultural aspects of society and is expressed in laws, values, and beliefs.



**Figure 1.** Bronfenbrenner's (1979) ecological model.

# AIM

The overall aim of this thesis was to illuminate in what way children in families with parental mental illness are taken into consideration in family interventions in psychiatric and social services, and how families experience the support they receive.

## Specific aims:

To investigate how professionals who work with affective disorders, in adult psychiatric outpatient services, deal with children and others in the family when a parent has a mental illness. The aim of the study was also to examine the way professionals identified parents with mental illness and their attitude towards supporting both the families as a whole and the children (study I).

To investigate the experiences of a representative group of professionals working in children's social care services, where they provide support to families and children when a parent has a mental illness (study II).

To investigate if families with parental mental illness treated for mental illness by psychiatric services are provided with child-focused interventions, and whether these families are involved in any interagency collaboration. An additional aim was to establish whether this collaboration is related to the parents' gender, diagnosis, comorbidity, and treatment in in- or outpatient care (study III).

To explore how families in which a parent is diagnosed with a mental illness and supported by family interventions in psychiatric services experience their situation. An additional aim was to examine the support provided by the family intervention and how family members experience this (study IV).

**Table 1.** Overview of the studies included

Study	Aim	Design	Setting	Participants	Data collection	Data analysis
I	Investigate how professionals in adult psychiatric outpatient services who work with affective disorders deal with children and others in the family when a parent has a mental illness. The study also aims to examine the way professionals identified parents with mental illness and their attitude towards supporting both the families as a whole and the children	Qualitative Interview study	Two outpatient psychiatric services in Psykiatri Skåne working with affective disorders	A total of 24 professionals were interviewed, five persons were individually interviewed and 19 professionals participated in four focus group discussions.	Individual interviews Focus group discussions	Inspired by inductive content analysis, and naturalistic inquiry; manifest level
II	Investigate the experiences of a representative group of professionals working in children's social care services, where they provide support to families and children when a parent has a mental illness	Qualitative Interview study	Two children's social care services in Skåne	A total of 13 professionals were interviewed, four persons in individual interviews and 9 persons in two focus group discussions	Individual interviews Focus group discussions	Inspired by inductive content analysis, and naturalistic inquiry; manifest level
III	To investigate if families that include a parent being treated for mental illness by psychiatric services are provided with child-focused interventions, and whether these families are involved in interagency collaboration between psychiatric services, social services, and child and adolescent psychiatry. An additional aim was to establish whether this collaboration is related to the parents' gender, diagnosis, comorbidity and treatment in in- or outpatient care.	Quantitative approach	Psykiatri Skåne	The study sample consisted of 29,972 individuals: 3,863 of whom were listed as parents of children under the age of 18	All patients registered in adult psychiatric care by Psychiatry Skåne, and two private psychiatric clinics, on 1 June 2014.	Descriptive statistics Pearson's chi-squared test Binary logistic regression
IV	Explore how families with a parent diagnosed with a mental illness and supported by family interventions in psychiatric services experience their situation. An additional aim was to examine the support provided by the family intervention and how family members experience this support	Qualitative Interview study	Patients were recruited by professionals in Psykiatri Skåne	Five families, nine adults and six children.	Individual interviews Family interviews	Inspired by inductive content analysis, and naturalistic inquiry; manifest level

# METHODS

## Design

In this thesis both a qualitative and a quantitative methodological approach were used in order to gain a deeper insight into how children of parents with a mental illness are taken into consideration in psychiatric and children's social care services when a parent is supported with a family intervention. Study I, II, and IV were conducted using a qualitative approach, since interviews is a way of gaining insight into the experiences of professionals and families (Kvale, 1997; Taylor & Bogdan, 1998). Study III was carried out as a quantitative study using a psychiatric service's medical record database to describe how children of parents with a mental illness are supported in a clinical context. Table 1 shows an overview of the four studies.

## Settings

The studies were conducted in the region of Skåne in southern Sweden. This part of Sweden has approximately 1.2 million inhabitants, 260,000 of whom are under 18 years of age. The area is divided into 33 municipalities with between 7,139 and 312,994 inhabitants in each one (Statistics Sweden, 2013). Each municipality has social services, including children's social care services.

The specialist psychiatric care is provided by Psykiatri Skåne, with the task to provide psychiatric care for individuals whose mental illness is so serious that specialist care is needed (Psykiatri Skåne, 2016). Patients suffering from minor mental illnesses are supposed to seek psychiatric care in the primary care. Psykiatri Skåne consists of child and adolescent psychiatry, adult psychiatric services, and forensic care within the region. The adult psychiatry is divided into services for people with affective or more general psychiatric diagnoses and psychiatric services for people with psychosis diagnoses. The specialist adult as well as the child and adolescent psychiatry services care are organised with inpatient and

outpatient services, each with different catchment areas of responsibility. In total, 32,712 patients were registered with the psychiatric services on 1 June 2014.

Three studies were linked to Psykiatri Skåne: one interview study with professionals in two outpatient services caring for people with mostly affective disorders (study I), one register study (study III), and one interview study with patients, and their families, receiving psychiatric adult services (study IV). The fourth study was an interview study with professionals linked to two children's social care services in two municipalities (study II).

The two municipalities in study II, located in the middle of Skåne, serve around 15,000 to 18,000 inhabitants, with both a rural environment and small towns. Both services included in the study used BBIC (National Board of Health and Welfare, 2013b), a systematic framework for assessment, planning, and reviewing in child welfare, which provides a structure for collecting information and documenting children's and young people's need of services.

## **Study I**

### **Data collection and procedures**

Professionals from two outpatient clinics caring for patients with affective disorders were invited to participate. These clinics were chosen by convenience, since patients diagnosed with affective disorders are more often parents of underage children (Östman & Eidevall, 2005) and since they responded positively when they were asked to participate. In order to get a broad knowledge of how children are taken into consideration when professionals treat patients that are also parents of underage children, both focus group discussions and individual interviews were carried out (Kvale & Brinkmann, 2009; Morgan & Scannell, 1998).

The head of each outpatient clinic was informed about the study, and accepted participation in the study. In one unit the head suggested professionals with a specific interest in child and family work for participation in both the focus groups and the individual interviews. The names of these professionals were given to the first author, who then contacted each person with both written and oral information about the study and about the fact that taking part in the study was voluntary. The decision to take part in the study was made by each professional, individually, and each professional also suggested an appropriate time for the interviews. For the focus group discussions, the head of the unit suggested times that were available for all the participants, and the participants agreed to this.

The head of the other outpatient clinic asked a professional to act as a contact person for the research group, and suggested three focus groups, one

with specialized social workers and the other two with interdisciplinary teams. The first author was given the professionals' names and contacted each person with information about the study and about participation being voluntary. Two professionals chose not to take part in the interview. The time for each individual interview was chosen by the participant, and the contact person suggested that the focus group discussions should be part of the outpatient clinic's regular team session, which the participants agreed to.

The interviews were held between May and October in 2013. They took place in the psychiatric services' locations – the focus group interviews in a group study room, and the individual interviews in the professional's own office. All the focus group discussions were led by the first and the second author of the study and the individual interviews were conducted by the first author. In the beginning of each interview, each participant answered a few questions concerning their age and professional background.

The focus group discussions started with a vignette (see Appendix 1). Prior to the focus groups settings, three different suggestions for a vignette were created, and all researchers in the study team discussed and decided which of these could be used. The vignette was presented to the focus groups as a text on a piece of paper describing a family with two children aged 12 and 16. The father in the vignette suffers from anxiety, with suicidal thoughts, and suspects that his wife has an extramarital love affair. The parents argue loudly and the wife leaves the house for a couple of days. The father is treated in inpatient psychiatric care and is permitted to go home for a few days. This vignette was used as a starter, with a realistic scenario intended to encourage the participants to bring forth their thoughts and reactions, in accordance with Bryman (2012), and it was followed by the open-ended question, "How would you work with a family like this?" (Appendix 2a).

The focus group discussions followed Wibeck's (2010) suggestions, with opening questions, key questions, and closing questions with an opportunity for the participants to give feedback. The data was generated through the interaction in the group discussions, where the professionals were able to share and argue for their thoughts and beliefs concerning how and why they would work with families with parental mental illness, in order to make collective sense of their individual experiences, in accordance with Morgan (1997).

The individual interviews were semi-structured with open-ended questions (Kvale, 1997), formulated like this: "When you meet your patient's family, how do you usually proceed?", "During what circumstances do you invite the patient's children and family?" (Appendix 2b).

The focus group interviews lasted between 71 and 85 minutes (mean time: 76 minutes), and the individual interviews between 36 and 51 minutes (mean time:

45 minutes). The interviews were recorded and transcribed verbatim by the first author and resulted in 140 pages. The data was preserved in a computer without connection to the internet and the paper copies were locked up in a firesafe cupboard.

## Participants

A total of 24 professionals participated in the study, five persons (three women and two men) in individual interviews, and 19 persons (16 women and three men) in focus group discussions. Four focus group discussions were performed, with four to six persons in each. The participants were employed as social worker (9), psychologist (5), nurse (5), occupational therapist (1), psychiatrist (2), and physiotherapist (2). Their average age was 52 years (range 24 to 66). Most of the participants had worked for a long time in psychiatry, and the majority of the professionals had some kind of psychotherapeutic education; seven persons held postgraduate diplomas in psychotherapy, with specializations in psychodynamic therapy, cognitive and behavioural therapy, and family therapy, six professionals had taken a basic course in psychotherapy, and three persons had specialist-nursing education in psychiatric care.

## Analysis

The interviews were coded in order to secure confidentiality. The process of analysing the data was inspired both by the inductive content analysis proposed by Elo and Kyngäs (2008), and by naturalistic inquiry (Lincoln & Guba, 1985). The transcribed interviews were analysed on a manifest level, and this was done in several steps. In order to familiarise with the data and gain a sense of wholeness of the material, each interview was read, reread, and listened to several times (Kvale & Brinkman, 2009). The individual interviews and the focus group discussions were analysed separately and then brought together in a joint analysis. The next step was to organise the data; an open coding was made, and notes were written in the text, while reading it, in order to describe the material. This was followed by writing all the notes on a sheet, and then grouping them under a higher order heading, in order to reduce and condense the preliminary categories, and provide a comprehensive view of the material. While grouping the data into categories, a comparison with the transcribed material was made repeatedly. All the authors had discussions and made revisions throughout the analysing process.

## Study II

### Data collection and procedures

Seven services in seven municipalities were asked if they could participate in the study. Two children's social care services decided to participate, whereas the other services said that they could not spare the time, and that they were in the middle of a reorganisation process. To collect data, both focus group discussions and individual interviews were chosen, in order to catch both the group perspective and the individual thoughts. The head of each of the two children's social care services that wanted to participate was informed about the study by the researcher, and the first author also attended a meeting at one service to present the study. The head of each service recommended participants, that is, persons who were working with families and who might be willing to attend either focus group discussions or individual interviews. At the first service, five children's social workers agreed to participate in a focus group discussion, and two professionals agreed to participate in individual interviews. At the other children's social care service, four social workers agreed to be interviewed in a focus group discussion, and two social workers agreed to participate in individual interviews. The first author was provided with the professionals' names by each head of the services, and all participants were contacted by the first author and informed about the study and about the fact that participation was voluntary. One professional that should have participated in a focus group discussion fell ill and could not participate.

All interviews were held between June and October in 2013. The interviews were located at the children's social care service; the focus group discussions took place in a group room, and the individual interviews in either the professionals' own offices or in a specific meeting room at the service. All the focus group discussions were led by the first and the second author, and the individual interviews were all conducted by the first author. In the beginning of each interview, each participant answered a few questions concerning their age and professional background.

The focus group discussions began with the same vignette as in study I (see Appendix 1) and it was followed by the same open-ended questions (see Appendix 2a and 2b). All data gathering was accomplished in accordance with the principles in study I.

The focus group interviews lasted between 78 and 93 minutes (mean time: 85 minutes), and the individual interviews between 28 and 65 minutes (mean time: 43 minutes). The interviews were recorded and transcribed verbatim by the first author and resulted in 99 pages. The data was preserved in a computer without connection to the internet and the paper copies were locked up in a firesafe cupboard.



## Participants

Thirteen people (twelve women and one man) participated, all of whom worked as social workers in specialized children's social care services. Two focus group discussions, with four and five people respectively were organised, and four people were interviewed individually. Eleven participants were educated as social workers, one participant had a social pedagogy education, and one participant was a treatment assistant. The average age of the participants was 44 years (range 29 to 57). The length of time in the profession varied from 3.5 years to 34 years. Two of the participants also worked as managers. Several of the social workers had additional training and education in Komet (a manual-based programme designed to support parents who feel that they are often in conflict with their child [National Board of Health and Welfare, n. d.]), Functional Family Therapy (FFT, a manual-based programme for families with adolescents with behaviour problems [National Board of Health and Welfare, n. d.]), and family- and group-related methods.

## Analysis

The analysis of the interviews followed the same principles as in study I.

## Study III

### Data collection and procedures

The data collection included all patients registered in adult psychiatric care by Psykiatri Skåne and two private psychiatric clinics, on 1 June 2014. The two private psychiatric clinics were included in the study since they had the same administration system for registering patients. A professional with administrative tasks, who was invited into the research project, collected data from Psykiatri Skåne's medical record database, including all patients over the age of 18 years that had had at least one contact with inpatient or outpatient care during the previous 12 months, and were either registered in the population register or asylum seekers. Patients born before 1945 were excluded, since none of them had children under 18 years of age registered in the database. Data concerning the patients included gender, main diagnosis, comorbidity, children of the patient, any child-focused intervention, and treatment in in- or outpatient care. The data was anonymized for the research project.

## Participants

The 32,712 patients registered with the psychiatric services were born between 1912 and 1994. The study population consisted of 29,972 individuals,

53.8% women and 46.2% men, born between 1945 and 1994, and registered as psychiatric patients in Psykiatri Skåne on 1 June 2014. The final study population consisted of 3,863 individuals listed as parents of children under the age of 18. Among the 3,863 patients, 1,144 (29.6%) had been involved in at least one child-focused intervention.

## Measures

Patients with children were defined as those registered in the database as having at least one child under 18 years of age.

### *Main diagnosis*

Regarding the main diagnoses and the comorbid diagnoses, the ICD-10 classification system was used (World Health Organization, 1992). They were grouped as follows: schizophrenia (F20-29); mood disorders (F30-39); neurotic, stress-related and somatoform disorders (F40-48); substance abuse (F10-19); behavioral and emotional disorders (F90-98); and personality disorders (F60-69). "Other disorders" included: less frequent main diagnoses categorized such as organic disorders (F00-F09); behavioral syndromes associated with physiological disturbances and physical factors (F50-59); mental retardation (F70-79); disorders of physiological development (F80-89); unspecified mental disorder (F99); and factors influencing health status and contact with health services (Z00-Z99). Patients with no main diagnosis were classified under "no main diagnosis".

### *Child-focused interventions*

Child-focused interventions were divided into two variables: those from adult psychiatry and those from interagency collaboration. This was done in order to clarify to what extent social services or child and adolescent psychiatry were involved.

Child-focused interventions from adult psychiatry were defined in accordance with the listed alternatives described in Psykiatri Skåne's guidelines (n.d) as follows:

- 1) Let's Talk about the Children (yes/no) (Solantaus & Toikka, 2006).
- 2) Beardslee's family intervention (yes/no) (Beardslee, 2002).
- 3) Information; providing the patient with information, advice, and support concerning the patient's children. Family sessions (a meeting of professionals with the patients and their families), and Session only with the child (a one-to-one session with the child and a professional) (yes/no).
- 4) no child-focused intervention as no.

From those four alternatives a new dichotomous variable was designed, with at least one child-focused intervention as yes, and no child-focused intervention as no.

Interagency collaboration was divided into three categories: patients with contact with social services, patients who had contact with child and adolescent psychiatry (with or without social services), and patients with no child-focused intervention.

## Analysis

### *Statistical analysis*

A statistical analysis was executed using SPSS 23.0 software, and a descriptive analysis was performed to present the study population. Differences between the categorical variables were analysed by Pearson's  $\chi^2$ -test. A binary logistic regression analysis was performed for associations between the dependent variable "interagency collaboration" and the variables "gender", "main diagnosis", "inpatient care", and "child-focused intervention" in adult psychiatry. The significance level was set at  $p < .001$  due to the large sample size.

## Study IV

### Data collection and procedures

Professionals in psychiatric services and children's social care services who had participated in interviews in studies I and II were asked if they could propose patients for participation in this study. The participants had to be parents with a diagnosis of mental illness, with children between 10 and 18 years, and who had been given a family intervention. The professionals received both written and oral information about the study, including information that participation was voluntary, in order to inform the presumed patient that was interested in taking part in the study. To collect data, both family interviews and individual interviews were chosen, since a single family member's view of experiences does not necessarily represent the whole family's experiences (Åstedt-Kurki & Hopia, 1996).

Two patients who fulfilled the inclusion criteria were recruited from the psychiatric services in this phase of the study, and they and their family members agreed to be interviewed. Professionals from the children's social care services were not able to recruit any participants at all. According to the professionals, it was very difficult to recruit families. To obtain sufficient data for the analysis, the children's representatives – professionals in psychiatric services who have a special task in addition to their regular professional duties, namely, to pay attention to patients that are parents and their children in order to support them,

and also to support colleagues in questions about families and children (Östman & Afzelius, 2011) – in the five areas of practice in Psykiatri Skåne, were asked for participation in the recruiting process. Five patients were engaged in this phase of the study and agreed to participate, and they confirmed that their contact information could be used so that the first author could get in touch with them to decide the time and place for the interviews. One family subsequently decided not to participate, and one patient/family could not be reached.

All patients were contacted by phone by the first author, and informed about the study, and about the fact that participation was voluntary. The patient was also asked to inform his or her family members about the study and ask if they would like to participate. Written information about the study was sent to the patient. The interviews were held between May 2013 and December 2015. The families chose the location and the time for the interviews.

All families that had received a family intervention from the psychiatric services, and who had experience of family meetings, were interviewed as a family unit. After the family interview, each family member was interviewed separately. Those family members that had been supported with parent support groups and child support groups in the psychiatric services, were interviewed individually.

This resulted in three families that were interviewed both as a family unit and individually, in their homes. The other two families were interviewed individually, both at home and at the outpatient clinic. In one of those two families, the patient and the child were interviewed one at a time at the outpatient clinic, and the partner at home. In the other family, the patient with mental illness was interviewed at the outpatient clinic, and the partner and the child together in a family interview at home.

Before interviewing family members, and in order to ensure emotional safety (Åstedt-Kurki & Hopia, 1996), the participants were once more informed both orally and in writing about the study. It was also made clear to the participants that their participation was voluntary and that they did not have to give any information if they did not want to. Moreover, the participants were informed that everything they said would remain confidential, and that it would not be possible to identify any family member in the report of the study.

By starting with a family interview, the intention was to make the children feel more comfortable in the interview situation and with the interviewer, and after that proceed with the individual interviews. This procedure was suggested by Eder and Fingerson (2003). In those two families without previous experience of family meetings, the interviewing began with the parent individually, and was then followed by individual interviews with the other family members. In another

family, the child requested to be interviewed with the partner of the mentally ill parent, which was complied with.

All the interviews were performed with open-ended questions. The family interview questions were: “What was the situation in the family when a family intervention was proposed?”, “When did you receive the invitation and how did your family react to this proposal?”, “How did you find the family intervention?”, “Did you discuss the family intervention at home?”, and “How are things going now in the family?” (Appendix 3a).

The individual interviews included questions such as “How do you find it living in this family?”, “How did you react to the family meetings?”, and “How is your family doing now?” (Appendix 3b).

The interviews started with a short introduction by the interviewer about why the study was performed and about the importance of gaining the participants’ thoughts about their lives with parental mental illness and their experiences of the interventions.

The family interviews were held as group interviews where the participants were encouraged to speak freely with each other. The questions were discussed and reflected upon by each member at a time, so that all the members thus listened to each other’s stories, which were all regarded equally true, even if they appeared to contradict to each other, in line with Reczek (2014), Åstedt-Kurki, and Hopia (1996).

Since the families also consisted of children, their participation in the interviews was paid a special attention to, by starting the interviews with small talk, and juice and cakes were served. The children were asked by their parents to participate in the interviews. Out of 16 children belonging to the participating families, six children were interviewed. Eight children were under the age of ten, and were not included in the sample, and two 14-year-old children did not want to participate, according to their parents.

During one family interview, three children under the age of 10 years were present, since their parents did not want to leave them out. Throughout the interview they ran in and out of the room where the interview was taking place, watching TV at the same time. In another family interview a newborn baby was present.

The family interviews lasted between 30 and 60 minutes and the individual interviews between 10 and 60 minutes. All interviews were recorded and transcribed verbatim by the first author and resulted in 114 pages. The data was preserved in a computer without connection to the internet and the paper copies were locked up in a fire safe cupboard.

## Participants

Five families were interviewed in the study, nine adults (five women and four men) and six children (four girls and two boys). The adults were between 33 and 44 years of age. The children were aged 10 to 12. Seven of the nine adults were employed, one was on sickness benefits, and one of them was on sick leave and unemployed. The parents had a variety of occupations: economist, computer technician, truck driver, entrepreneur, and teacher.

In two families, the father had been diagnosed with depression in combination with attention deficit hyperactivity disorder (ADHD) and attention deficit disorder (ADD). In three of them, the mother told of being diagnosed with depression, and with comorbidity of bipolar illness and ADHD.

The families varied in their compositions (Table 2). In one family, the father lived with his wife and their two children together with his wife's three children from a prior marriage. One family was a single-parent family with a mother and four children by three different fathers. Other families involved were a couple with a newborn and another child, a family with two children, and one with three children.

## Analysis

In study IV, the analysing process of the data was inspired both by the inductive content analysis proposed by Elo and Kyngäs (2008) and by naturalistic inquiry (Lincoln & Guba, 1985). The interviews were coded in order to secure confidentiality. The transcribed interviews were analysed mainly on a manifest level and in several steps. Each interview was read, reread, and listened to several times to gain a wholeness of the material, in accordance with Kvale & Brinkman (2009). The individual interviews and the family interviews were analysed separately and then brought together in a joint analysis. The next step was to organise the data; an open coding was made, and notes were written in the text, while reading it, in order to describe the material. This was followed by writing all the notes on a sheet, and then grouping them under a higher order heading, in order to reduce and condense the preliminary categories, and provide a comprehensive view of the material. While grouping the data into categories, a comparison with the transcribed material was made repeatedly. All the authors had discussions and made revisions throughout the analysing process.

**Table 2.** Family members and their participation in the study

<b>Family composition</b>	<b>Family interview participants</b>	<b>Interviewee with parental mental illness</b>	<b>Interview with partner</b>	<b>Interview with child</b>
Family 1: mother, father, 2 daughters, 1 son	father and daughter	mother		
Family 2: mother, father, 2 sons		mother	father	son
Family 3: mother, father, 2 sons	mother and father	father	mother	
Family 4: mother, father, 2 sons, 3 daughters	mother, father and 2 daughters	father	mother	2 daughters
Family 5: mother, 3 sons, 1 daughter	mother, son, daughter	mother		son, daughter

## ETHICAL CONSIDERATIONS

The studies have all been approved by the Regional Ethics Review Board in Lund (Reg. no. 2013/137, 2013/305). An additional ethical approval for study IV was requested and granted (2015/444).

Mental illness can be perceived as a sensitive issue, and can include stigma and social shame. Even if professionals engaged in the care of people with mental illness are involved with their patients and their families, mental illness can be difficult to talk about. Professionals may feel guilty about not being able to support these families in the way they want to, and talking about this in interviews may constitute an ethical dilemma. However, talking about sensitive issues can also contribute to more openness about mental illness (Kvale, 2009).

Professionals in study I and II were all asked to participate by the head of their unit, and they might have experienced some form of pressure in participating in the study.

Since the studies included in this thesis involve interviewing children, special efforts were made to pay attention to them in the information letter, designed in order to be appropriate to the children's ages (Åstedt-Kurki & Hopia, 1996). Every interview with the informants started with brief information about the study, as well as information about the participants' right to leave the interview without explanation, and about the fact that deciding to be interviewed was voluntary. The children's voices are important and in order to support them, their thoughts and views need to be listened to, and this might be experienced as a relief for the children. Any negative experiences that the children might have had with regard to talking about sensitive issues could to some extent be reduced since the family was present during the interviews and since the parent's therapist had the possibility to provide support if this was needed.



# RESULTS

## Study I

The analysis resulted in two main categories evolving from the interviews. These were 1) Establishing a trustful relationship with the patient, and 2) Fulfilling legal obligations towards the child. Both main categories contained two sub-categories. The participants told of balancing between these categories.

### *Establishing a trustful relationship with the patient*

Two sub-categories, namely, a) establishing a care relationship, and b) protecting the care relationship, generated from the category Establishing a trustful relationship with the patient, described the importance of building and maintaining a relationship with the patient before initiating talks about the patient's children. The professionals evaluated their relationships with their patients before talking to them about introducing the patients' children and family as a whole in the treatment. Some of the participants thought it could be intrusive, or distressing, for the patients to be asked questions about the children and the family in general. In some cases, they noticed that the patient's children needed support, but they had to overlook this, in order to try to convince the patient to accept treatment in psychiatric care. The informants spoke of a dilemma when involving the patient's family in the treatment, both with regard to handling information from the family about the patient and with regard to sharing information about the patient with family members. However, families were seldom seen at the clinics. Professionals talked about lacking skills in working with families and children. Being aware of the patient's children, and taking them into account, was by some professionals assumed as a requirement from the organisation, but seen as a task that could be performed by others in the clinic.

### *Fulfilling legal obligation towards the child*

Two sub-categories, namely, c) looking for warning signs, and d) inviting the children and families needs flexibility, time and collaboration, formed the main category Fulfilling legal obligation towards the child. The interviews revealed the professionals' efforts in trying to be aware of and live up to the responsibilities of having a child perspective and a family approach even though they seldom met the families. When trying to invite the patient's family and children to participate in the treatment, they experienced several difficulties both from the patient and from the organisation; either the patient seemed unwilling, or the family members showed up at another time than planned in the beginning. When families showed up in treatment, this required flexibility from the professionals, regarding space, time, and how to monitor a meeting with children of different ages and needs. Professionals also spoke of difficulties in establishing collaboration with other services and making time for this.

## **Study II**

The analysis resulted in two main categories: 1) Identifying with the situation of the child, and 2) Handling parental SMI (serious mental illness) when not a specialist worker in mental health. The first main category included two sub-categories, and the second main category involved four sub-categories.

### *Identifying with the situation of the child*

The two sub-categories, namely, a) supporting the child's needs, and b) parental SMI is not a children's social worker's main focus, formed the category Identifying with the situation of the child. The social workers spoke of their overall assignment of identifying the needs of the child. They were striving to support the children in families, trying to unburden them from feeling responsible for their parents. Having a child perspective, and involving the children to some degree, was important. However, when sensitive issues were spoken of in the family interventions, it was not necessary for the children to participate. Families with parental mental illness were looked upon as any other families, with the same rights to support. Professionals had different opinions of parental mental illness and its effect on children. When there was a healthy spouse in the family or the child did not exhibit any externalised behaviour, they did not intervene. The social workers talked about using a systemic thinking about family interventions, and working with the families' basic needs.

### *Handling parental SMI when not a specialist worker in mental health*

The four sub-categories, namely, a) identifying a parent's SMI, b) losing the focus on parenting, c) setting the children's perspective aside, and d) collaborating with psychiatric services, were linked to the other main category, that is, Handling parental SMI when not a specialist worker in mental health. The social workers talked about working with the parent's parenting role, and a parental mental illness could make this support difficult. It was particularly difficult when the parent did not realize that he or she had a mental illness or had problems coping with it. The social workers wanted the parent to seek help, but this depended on the parent's motivation. In cases where the informant assessed that the parent was in need of psychiatric support and did not receive such support, or when the parent's needs were perceived as demanding for the social worker, it was difficult to also make space for the child's needs. The difficulties of collaboration with the psychiatric services regarding these parents' needs left the informants with a feeling of "being the last outpost" for families with parental mental illness. One way to solve the collaboration difficulties could be by using a coordinated individual plan (SIP), but this opportunity was seldom resorted to.

### **Study III**

#### *Patients with registered children, main diagnoses, and occurrence of child-focused intervention and interagency collaboration*

Out of 29,972 patients, 3,863 (12.9%) were registered as parents of children under the age of 18 years. Men were less frequently registered as having children than women (men 9.9%, women 15.5%). When comparing their main diagnosis with all other main diagnoses, patients with schizophrenia (6.4%) were less likely to have registered children, whereas patients with behavioural and emotional disorders (17.1%), neurotic stress-related disorders (16.3%), and mood disorders (15.7%) more often had registered children. About one fourth of the patients with registered children received child-focused interventions from adult psychiatric care (23.7%). Women (26.6%) and patients with inpatient care (34.1%) more often received interventions from adult psychiatry than men (18.4%) and patients without inpatient care (22.2%). Among all patients with registered children, 13.2% were involved in interagency collaboration.

Patients with registered children who had received inpatient care during the previous 12 months more often had contact with the social services (22.4%) than patients that had only received outpatient care (7.7%). Further, patients who had been supported with Beardslee's family intervention more often had contact

with the social services (14.7%) or child and adolescent psychiatry (19.1%), than other patients with registered children.

Patients with a main diagnosis of schizophrenia more often received at least one intervention from adult psychiatry (43.6%) than patients with other diagnoses (22.8%).

Patients with registered children and with a main diagnosis of substance abuse (34.4%) or schizophrenia (18.4%) were more often involved with the social services compared to all other main diagnoses.

Among the patients with registered children, 33.9% had a comorbid diagnosis and out of these 26.7% were provided with at least one child-focused intervention from adult psychiatry, as compared to 22.2% among those without a comorbid diagnosis. Moreover, these patients had more contact with the social services (10.1%) or child and adolescent psychiatry (5.6%) than those without a comorbidity (9.3% and 2.7%).

#### *Child-focused interventions in adult psychiatry in relation to interagency collaboration*

Patients who were supported with child-focused interventions from adult psychiatry were more often involved in interagency collaboration than patients who had not been supported with child-focused interventions from adult psychiatry (30.7% vs 7.7%).

A logistic regression analysis was performed in order to investigate associations between child-focused interagency and a number of variables of interest. Interagency collaboration was five times more likely to occur if substance abuse was the main diagnosis as compared to other main psychiatric diagnoses. Also, when child-focused interventions had been given by adult psychiatry, interagency collaboration with other services was more than five times more likely to occur.

#### **Study IV**

The overall category, Trying to lead an ordinary life, captured the sense of how these families struggled in their daily life. From this main category emerged five sub-categories: 1) Using strategies to maintain an ordinary life, 2) Adjusting to the needs of the ill parent, 3) Concerns for the child's needs and seeking support, 4) Balancing one's own life and the demands of the parental mental illness, and 5) The partner in the shadow of the parental mental illness.

The families in our study all spoke of how they strived to lead an ordinary life, and not to let the children be involved in the parental mental illness. Both partners and children talked about how they adjusted to the parental mental

illness. Children tried to help in the household, by either comforting or arguing with the parent, or they withdrew to their rooms. Some children talked about being constantly worried. The parents experiencing mental illness felt guilty about not coping with family life and children, and they were eager to find support from the psychiatric services in order to get help to explain to their children about their mental illness. Children joined these meetings in the psychiatric service when the parent asked them to. Parents experiencing mental illness felt satisfied with the family intervention and spoke of balancing their own life and the demands of the parental mental illness. Children said that there were fewer conflicts in the household after family interventions, and the parents said that they took more responsibility and were sensitive to the children's needs. Despite efforts from the family intervention, some children were still worried about what the parental mental illness could imply. As for the partners, they felt ignored; they did not receive support from the psychiatric service, and not all of them had been invited to family meetings.

# METHODOLOGICAL CONSIDERATIONS

## Data collection and procedures

### Study I and II

When the design for the studies was set up, an initial intention was to recruit psychiatric and children's social care services that were linked together geographically, since this might have brought forth useful thoughts and had interesting implications for the work with families with parental mental illness. However, this was not feasible since the recruitment process for the study dragged on due to organisational problems in the children's social care services.

In studies I and II, participants were chosen by staff leaders, and not by means of a random selection. This might have affected the data collection and the analyses of the studies (Bryman, 2012), since professionals with other and perhaps more critical voices might have been excluded in the studies. However, the data collection involved two focus group discussions with interdisciplinary teams in the psychiatric service and two focus group discussions in the children's social care service, which may have reduced any biases in the data collection. By involving pre-existing groups where the participants were colleagues and worked daily with the questions under study, a variety of voices, both positive and critical ones concerning working with parental mental illness, were collected. Furthermore, the discussions reminded the participants of actual cases where they made comments to each other and discussed their approaches to families with parental mental illness, just as in their shared daily working life, which is in line both with the suggestions from both Kitzinger (1994) and Lincoln and Guba (1985).

Study I and II had a similar methodological approach in collecting data. The choice of focus group discussions was based on the fact that these group discussions are useful in understanding professionals' attitudes to and beliefs about a specific, known subject, since attitudes and beliefs are constructed in the

interaction with other members in the group (Merton, Fiske, & Kendall, 1990). The vignette in the focus group discussions was used as a starter to stimulate the participants to discuss and think about the case described, in line with Wibeck's (2010) suggestion of how to encourage the discussion. In the individual interviews, the vignette was not used, which might have had an impact on the analysis and the results, since if the interviewees would have had any specific thoughts concerning the vignette, this information is not included in the data.

However, discussing how parental mental illness is dealt with in psychiatric and social care can be sensitive, since some participants might not want to speak, due to, for example, hierarchical structures, their own personal feelings, and/or power relationships among the participants (Mitchell, 1999). In order to create an open atmosphere, all participants' opinions were confirmed and no participant was forced to speak (Wibeck, 2010). Furthermore, no participant spoke of being afraid of talking and sharing thoughts when asked about this; instead some groups spoke of their need to discuss how to approach families with parental mental illness in their organisation.

In the individual interviews, the participants had the possibility to speak freely about the topic, which might have encouraged them to be more open. However, opinions and thoughts may be easier to express when the interview involves more than two persons, provided no participant feels left out (Kitzinger, 1994). But since the purpose of collecting data in two different ways was to capture a broad knowledge of how professionals work with parental mental illness in families, both methods were used.

### Study III

Although register data might be robust data, and not influenced by self-reported data, limitations in study III were that the data was restricted to the variables in the register, and that the findings are not checked in a clinical context. A strength of this study is that from a comprehensive database it is possible to identify both the number of patients with registered underage children, and their received child-focused interventions and interagency collaboration. Moreover, several studies concerning parents with a mental illness involve mostly mothers (Dolman, Jones, & Howard, 2013), while this study also included fathers.

### Study IV

When asking a parent about interviewing their family, it must be kept in mind that the word family has several meanings. A family can consist of a variety of constellations, thus defining itself by its members. It has been asserted that

contemporary families are defined more by “doing family” than by “being family” (Morgan, 1996). By using the broad definition of family, suggested by Eggenberger and Nelms (2006) and Piltz and Gustavsdottir (1995), we thought that more families might be interested.

In study IV, the recruitment of families was mediated by professionals in the relevant services. In children’s social care services, the professionals did not find any suitable families. The professionals mentioned several reasons for not being able to recruit families, such as lack of time to ask parents to participate, and the fact that the families were already in a burdened situation, which is in line with the findings of other studies (Sharkey, Saulescu, Aranda, & Schofield, 2010; Thomas, Plant, Woodward-Nutt, Prior, & Tyson, 2015). Further reasons were that the professionals experienced that the relationship to the parent needed to be protected, and that professionals in children’s social care services found it difficult to identify parental mental illness. According to Bryman (2012), gaining access to interviewing families is facilitated by gatekeepers, people that are concerned about the research and how it can influence their organisation, and willing to expose the service even though it can potentially risk its image. However, we did not manage to find gatekeepers that enabled the process, in study IV, although the head of the unit accepted the research project. The recruitment of the patients was found to be transferred to each professional’s own agenda.

In order to broaden the data collection in the psychiatric services, more units than the two that were first chosen were involved. However, the small number of families identified might indicate that most families are not receiving family interventions, or might not need them. It might also – and this is perhaps more likely – indicate that the psychiatric services seldom work with the whole family, since it is known that psychiatric services by tradition work with their patients individually (Maybery & Reupert, 2009).

A strength of this study is the focus on the whole family in collecting data. Families that had been provided with family meetings were interviewed as a unit, and families that had been supported with parent support groups and child support groups were interviewed individually. Furthermore, as shown in studies I and II, certain topics may be sensitive to discuss together with a sick family member, and need to be followed up in individual interviews (Mitchell, 1999; Reczek, 2014).

All children aged between 10 and 18 years were invited to participate in the study, but no child over 12 years took part. The age span of inviting the children was decided in accordance with the Ethical Board decision, first and foremost to avoid enforced participation from younger children. The children were asked to participate by their parents. When interviewing children that the interviewer has



met only for a short while, specific attention has to be paid to both the interview questions and the ethical needs. Since one of the purposes of interviewing children in study IV was to explore children's experiences of family interventions and obtain descriptions of their daily life with a parent with mental illness, it was important to listen to their voices. Some of the children seemed to be shy in the beginning and gave only brief answers to the open-ended questions. However, after a while they were more outspoken. Informing the child during the interview that it was important for the first author to learn how children with a parent with a mental illness experience support, seemed to make the child interested in sharing his or her thoughts, which is in line with Solberg (2014). In the family meetings, the parents had encouraged their children to speak, and told them that it was allowed. However, one child did not want to be interviewed alone, but with her father, a wish that was granted.

One way of understanding why the children over 12 years in this study did not want to participate might be that they exercised their own free will or that the time schedule did not fit their spare time activities. Another explanation might be that teenagers can be less controllable for the parent and that their view of living with a parent with mental illness could reveal difficulties that the parent is perhaps not willing to share with the researcher. Children's position in society has changed and gone from children being viewed as dependent and vulnerable to being viewed as social actors, with the right to speak, be heard, and make their own decisions according to their ages (Sallnäs, Wiklund, & Lagerlöf, 2010). Since children's voices of all ages about living with a parent with a mental illness are an important source for understanding how these children are doing, it might be a drawback that the teenagers did not participate.

## **Analysis**

### **Trustworthiness**

In order to ensure the trustworthiness of the data (in Study I, II, and IV), which involves its credibility, transferability, confirmability, and dependability, it is, according to Lincoln and Guba (1985) and Elo and Kyngäs (2008), important to explain and critically reflect on all the steps taken in the research project, so that readers can validate the precisions of the interpretations carried out.

Credibility refers to how well the method, the participants, and the analysis reflect the subject of the study in a reliable way (Elo & Kyngäs, 2008). All the different steps in the research process, as well as the participants and the methods, have been carefully described in the studies. Furthermore, in order to increase the credibility of the studies, the co-authors have been involved in all the steps in the research process.

The transferability of the results denotes a description of the context of the studies, of how the participants were selected, and of the data collection, as well as of how the process of the analysis was performed, in order to give the reader a possibility to follow the process and the findings. As shown in all qualitative studies in this thesis, the number of participants was small. However, the intention of the studies was not to generalise the findings, but rather to describe a phenomenon. With more resource-intensive methods, such as observational studies and studies of case material, the picture of the experience of professionals in psychiatric and social services would have been expanded. When analysing the data as a whole, a shortcoming can be noticed. A common way to use focus group discussions and family interviews is to also explore the relationships between the members in the groups (Donalek, 2009; Kitzinger, 1994). This was not the intention of the studies included in this thesis, however, although the relationships between members could have provided valuable information regarding the findings of the studies.

Choosing a research method to capture complex phenomena includes being aware of one's own preconceptions concerning the subject. According to Lincoln and Guba (1985), the researcher always has to reflect upon how the research process has been influenced by the researcher. The first author has been working as a social worker in psychiatric services for over 25 years. Being part of a structure inevitably involves preconceptions, in this case concerning the psychiatric services and the work with the patients' families and children. However, studying literature about family involvement and children's participation in care, and interviewing professionals in psychiatric and children's social care services, as well as families, might have contributed to the first author gaining other perspectives on the issue, since preconceptions are not stable but processed during research work (Thomsson, 2002). Discussions with her supervisors and other colleagues have also contributed to making the first author pay attention to preconceptions and their possible influence on the thesis. Moreover, preconceptions may to some extent be of value in striving to understand children and families with parental mental illness.

However, in order to establish confirmability, or objectivity, of the data and in interpretations of the material (Bryman, 2012), there was an ongoing discussion of the material among all authors in the studies. In study I and II, the focus group discussions were conducted by the first and the second author, and discussions with the third author contributed to a deeper and more complex analysis. Further, the first author transcribed the material in studies I, II, and IV, the second and the third authors read summaries of the material, and all three authors identified

codes, subcategories, and categories in an ongoing discussion throughout the processing of the data. The discussion resulted in an agreement of the analyses.

In study III, the recorded data in the medical record database was registered by professionals themselves. This might indicate that the information recorded could vary depending on what kind of information the professionals had concerning the patient and on the professionals' knowledge concerning the child-focused interventions that the patient had received. Further, it was not possible to know which of a patient's children had received the child-focused intervention, and if the patient had twins or two children born in the same year, the database could only register one child. Another limitation is that the database did not include information of how the patient's contact with the social services or child and adolescent psychiatry had been established, if the contact with these services was ongoing, or who had initiated the contact.

## DISCUSSION

The ecological model by Bronfenbrenner (1979) was chosen because it can elucidate an understanding of how factors, such as the support that parents in psychiatric care are provided with, influence the family and especially the child.

### Relating to the law without practicing it

According to Bronfenbrenner's (1979) model, the macrosystem refers to the ideologies, belief systems, cultural beliefs, and laws that surround children. When the Swedish legislator instituted the above-mentioned addition in the Health and Medical Services Act (SFS 2017:30, 5:7), the purpose was to ensure that children living with parental mental illness are taken into consideration in health care, since parental mental illness can be a risk factor for children, leading to their developing their own mental health problems (Dean et al., 2010), to difficulties with attachment (Foster, O'Brien, & Mcallister, 2005), and to academic and behavioural problems (Reupert & Maybery, 2007). Sweden is not the only country that stipulates that the needs of these children and of the whole family have to be considered; in Australia, Norway, and Finland such legislation is also instituted. However, according to Bronfenbrenner (1979), if changes in the macrosystem are being made, this should influence the lower systems. A law can only have an impact on children living with parental mental illness if the law permeates all the other systems down to the child.

In the clinical context, these children have to be not only identified but also supported. How the law regarding children living with parents with mental illness is implemented can be seen in the microsystem as well as in the exosystem. The findings in study III showed that only 12.9% of 29,972 patients were registered with at least one underage child, and, compared to other studies around the world (Luciano et al., 2015; Maybery et al., 2009), it is a low figure. Furthermore, the study also showed that only a fourth of the patients with

registered children had received any child-focused interventions. Several reasons for this lack of registration and of received interventions can be found, reasons such as a complicated register system or lack of implementation of the guidelines. Despite the fact that the legislator also initiated a national project for providing education in Beardslee's (2002) preventive family intervention for professionals in psychiatric services, the implementation of the law in clinical practice cannot be considered sufficient. When professionals in psychiatric services were interviewed, it was found that they did not ask about the patients' children when they were unsure of the relationship with the patient or when they thought the patient might feel insulted or stressed by the question. However, the professionals' assumptions turned out to be mistaken, as the findings in this thesis showed that the parents expressed a wish to talk about their children and to be supported with information about mental illness to their families.

Furthermore, psychiatric services (placed both in the exosystem and in the microsystem) usually emphasize the individual perspective (Maybery & Reupert, 2009), which may impact negatively on the children's possibilities to receive support from family interventions, as shown in study III. A barrier to involving the parent's family in treatment is the lack of skills in family work (Foster et al., 2012; Maybery & Reupert, 2006) although some professionals in the study had education in family interventions and family therapy, they seldom used it. When they invited families, they noticed that family sessions were more time consuming than individual sessions, and in order to follow the demands from the management concerning the number of patients each professional should treat, family work did not seem an option. Some professionals told of supporting the children by talking about them in the therapy with their parent. This might support the children, but the children's own opinions about their needs are not heard. McConnell Gladstone, Boydell, and McKeever (2006) argue that children, even though they are vulnerable, can be viewed as competent social actors, and as able to contribute to social life, and that their experiences of living with parental mental illness can illuminate other perspectives of the situation than those described by their parents.

Professionals' attitude towards involving the patients' children can also be linked to their individual decision-making and the contextual structure they represent. According to Lipsky (2010), professionals in welfare organisations, such as psychiatric and social services, have discretion. These professionals interact directly with their patients and have a significant impact on their lives, since they, as representatives of the welfare services, can make decisions regarding suitable benefits and sanctions.

As shown in study IV, as well as in previous studies in this field of research (Foster et al., 2012), parents with mental illness want support in parenting. Parents may lose faith in their parenting capacity when, as found in study IV, the illness is overwhelming, and in these situations the parents seek to hide in order to protect their children. This behaviour made the parents feel guilty about not coping with their children. According to other studies, it is not unusual that the parents avoid talking about their children in treatment for fear of losing custody (Diaz-Caneja & Johnson, 2004), and being considered a bad parent. When psychiatric services are family oriented, the parenting role can be one of many focuses in a psychiatric contact, and this is, thus, a support that can be provided both in the exosystem and in the microsystem.

Professionals in both study I and II spoke of the need of being observant of children of mentally ill parents by looking for warning signs and examining risk factors while listening to the parents. Both the exosystem and the microsystem are involved when assessing whether a child is at risk of harm, which is a complicated task. The risk assessment involves professionals' expertise and emotions, as well as the guidelines and traditions of their workplaces with regard to handling these cases (Svård, 2016). The risk factors for children living with a mentally ill parent have earlier been shown to be higher compared with other children without a parent with mental illness (Beardslee et al., 2011), and the risk assessment is an important task for professionals in protecting children from further risks (Murphy, Peters, & Wilkes, 2015). However, the stigmatization related to mental illness and parenting, or the risk discourse that can be found in professionals' attitudes towards parents with mental illness (Boursnell, 2014), can prevent parents from disclosing their difficulties in parenting, and can also prevent professionals from working in a more family-focused way, where the children can be supported. Thus, the social workers in study II told of supporting all families alike without specific regard to the parental mental illness, an attitude that can be stigmatizing if it means that children and families are excluded from services needed (Van der Sanden, Kok, Bos, Sutterheim, & Pryor, 2015). In these situations, the parents might be unaware of the support they can obtain for their children and families.

In order to further prevent these children from being left without support, professionals who lack skills in family work may be given appropriate education in such skills, in line with the findings of Korhonen et al. (2010). If professionals gain knowledge in intervention programmes aimed at preventing child behavioural problems and improving parenting skills, they will be able to offer families with parental mental illness adequate support (Wansink, Janssens, Hoencamp, Middelkoop, & Hosman, 2015).

## Support systems that do not connect

The design of the support to families with parental mental illness in communities and regions might be of significance to children in families with parental mental illness (Reupert & Maybery, 2016). Collaboration is important, and the collaboration between welfare services concerning children living with parental mental illness, is, according to Bronfenbrenner(1979), situated in several systems, from the macro- to the microsystem.

In study II, the social workers were left with a feeling of being responsible for taking care of the parent's mental illness and in some cases they prioritized his or her needs instead of the needs of the child. Both individual and focus group discussions with social workers revealed that there was no consensus among them concerning the impact of parental mental illness on children, and that their assessments of the parents' needs for psychiatric care seldom matched the assessments made by the psychiatric services. Differences in understanding the parental mental illness have been found to influence the understanding of child protection needs (Darlington & Feeney, 2008), and might lead to maintaining the picture of children as invisible.

Professionals in both study I and II spoke of the lack of collaboration between them and blamed this lack on each other. However, the social workers are dependent on other medical services for knowledge and expertise that will help them to make adequate decisions concerning children's well-being (Levin, 2000). The social workers in our study told of being in a lower position in comparison to professions in psychiatry, as also shown in Stanley, Penhale, Riordan, Barbour, and Holden (2003). When the working culture influences in what way the children receive support, a possible way to prevent children from being without support is to work systematically to implement child and family work in the services (Danemark, Germundsson, & Englund, 2012).

In addition to this, study III showed that when the psychiatric services provided patients that are parents with child-focused interventions, the likelihood of being involved in interagency collaboration with other welfare services increased. However, the lack of interagency collaboration concerning these families and children is well known and has raised particular interest in a number of European countries (Hetherington, Baistow, Katz, Mesie, & Trowell, 2002; Vigano et al. 2017).

## The parent's psychiatric treatment: a support or a barrier?

In this analysis, the close relationship between the parent and the therapist belongs to the microsystem. In study IV, the parents told of having trustful relationships

with their psychiatric therapists, which might have contributed to enhancing the parents' courage to open up a communication about their children and parenting, and involving the family and children in the treatment, as also shown in Pihkala, Sandlund, and Cederström (2011b). The children spoke of fewer conflicts at home and less worries for their parents, and the parents felt supported in their parenting role, which is also in accordance with earlier studies (Reupert, Price-Robertson, & Maybery, 2017).

In contrast, study I found a fear among the professionals of breaching the confidentiality of the patient-therapist relationship, and this fear was considered a barrier to involving children and others in the treatment, as also shown in the findings of Marshall and Solomon (2003). According to Bronfenbrenner's (1979) theory, confidentiality can be placed in the exosystem as well as in the mesosystem and the microsystem. Medical confidentiality is central in the relationship between healthcare professionals and patients, and needs to be respected in order to protect the patient's "best interest"; it is also required when building a therapeutic relationship (Bennet, 2007). However, the assumption that talking about the children and parenting in the therapeutic session will result in the patient leaving the contact or being less motivated to proceed with it, may occur, but such an assumption is also a powerful way to exclude the patient's family from the treatment. In everyday life, the patient is a part of his or her family and depends on it (Lindemann, 2007). As for children, not including them in the parent's treatment might contribute to leaving them without support, and to the children seeing themselves as the reason for the parent's illness as well as taking a much larger responsibility for the parent than needed, in line with Östman's findings (2008).

Knowledge and information about the mental illness have a key role in psychoeducation as well as in family interventions (Foster et al., 2016). In order for both patients and families to manage mental illness in the family, an open communication and a willingness among the family members to share information are important. According to Marshall and Solomon (2003), one reason for professionals to consider confidentiality a dilemma, was unclear guidelines for professionals with regard to how to convey information to families. However, parents with a mental illness may also be opposed to involving family members in treatment because disclosure about mental illness can be stigmatizing, not only for the patient but also for the other family members (Maybery & Reupert, 2007; Rose, Mallinson, & Walton-Moss, 2004; Östman & Kjellin, 2002). Nevertheless, several studies concerning the opinions of patients in psychiatric services, with regard to involving their relatives in the care, show the opposite. They want their



relatives to be involved and to receive information about their mental illness (Oltedal, Garrett, & Johannessen, 2007; Rose et al., 2004; Vedel, Kessing, Vibe Hansen, Ruggeri, & Bech, 2006).

### The importance of the family and the partner

The family system is part of the child's microsystems. In study IV, all interviewed families were affected by the parental mental illness, a finding that is in line with Falkov (2012). The children talked about adjusting themselves to their parents' needs, by either comforting them or arguing with them when they thought the parents behaved badly. Some children fled to their rooms to seek solitude, and they all had worries for their mentally ill parent and wanted to help him or her feel better. Several studies show similar findings (Dam & Hall, 2016; Gladstone et al., 2011) and, as was also shown in study IV, peer relationships (the mesosystem) can be affected when the child chooses to stay at home to attend to the parent rather than meet with peers.

When partners are overloaded with household responsibilities and childcare, combined with worries for their spouses' health, the relationships to the children might be affected. Spouses have, in earlier studies, been shown to be inclined to feel stressed and to take a lot of responsibility when a partner is ill (Tranvåg & Kristofferson, 2008; Östman & Hansson, 2004; Östman, 2000). Furthermore, the relation between the mentally ill parent and the spouse can change as a consequence of the mental illness (Dahlqvist Jönsson, Skärsäter, Wijk, & Danielsson, 2011; Stjernswärd & Östman, 2008; Tranvåg & Kristofferson, 2008), and the partner may develop into being a carer for the ill partner (Stjernswärd & Östman, 2008). In addition, not all children grow up with two parents, as shown in one family in study IV. Studies show that when children live in families with one parent, and this parent has a mental illness, the parent in question is mostly the mother (Skerfving, 2007), who may have little contact with the father. In these cases, the support system has to pay extra attention to the single parent, who often has to struggle too long with his or her mental illness before seeking help, due to fear of the separation from the child during treatment and what this can lead to (Dolman et al., 2013).

# CONCLUSIONS

The findings show that few children of parents with mental illness are being supported by the psychiatric service, even though it is obligatory for professionals in health care to pay attention to those children. The findings also show a lack of collaboration between psychiatric services and children's social care. However, when families are involved in any child-focused intervention in the psychiatric service, the likelihood of being involved in interagency collaboration with other welfare services is increased. Thus, the psychiatric services have a key role in identifying parental mental illness, and in providing those of their patients that are parents and their children with adequate support.

The thesis illuminate a gap between professionals' assumptions about whether those of their patients that are parents want support in talking about and with their children about their mental illness, and the view of the patients themselves. Professionals hesitate in talking about these issues with their patient for fear of losing their contact with the patient, while the patients interviewed in this thesis had a trustful relationship with their psychiatric contact and wanted support in family matters.

Furthermore, if children of parents with a mental illness are to be supported in the psychiatric services, which is stipulated in the law (Health and Medical Services Act, SFS 2017:30, 5:7), the law has to have an influence on all interacting systems according to Bronfenbrenner (1979), from the macrosystem to the microsystem, surrounding the child. As shown in this thesis, there are a lot of obstacles to implementing support to these families, which might create problems when initiating the intentions of the law in everyday clinical practice, leaving children without support even though they are by law entitled to it. Although information about evidence-based models of intervention and family education have been provided to the professionals in these services, the efforts have proved insufficient. The findings show that the support from these children and families relies on the professionals' own discretion, rather than being a regular task.

## CLINICAL IMPLICATIONS AND FURTHER RESEARCH

Working with families with parental mental illness in the psychiatric services, where the treatment is usually focused on the individual, calls for a paradigm shift, whereby the individual perspective is supplemented with the family perspective.

The psychiatric service has to develop a family approach, that is, the treatment offered to families with parental mental illness has to be part of the basic treatments that all psychiatric patients can receive. Each family is different, and the need for support can vary between family members. However, as shown in this thesis, everyone in the family should be consulted, just as all patients with children should be consulted concerning the needs of their family, which might encourage professionals to open up for family approaches in their psychiatric treatment.

In order to make sure that children of parents with mental illness receive the support they need, systematic work has to be undertaken in the psychiatric service.

The social services, as well as the psychiatric services, and child and adolescent psychiatry, need to develop systematic collaboration in order to make adequate decisions concerning support to and protection of families with parental mental illness. Shared values and knowledge concerning these families can enhance the support for children and contribute to earlier interventions.

Society needs to support and help the development of a caring and trustful microsystem for children of mentally ill parents. The psychiatric services have a key role in identifying children of parents with mental illness, and have to take the responsibility of fulfilling this assignment. In order to support these children, professionals need to view the parents in the context of the social systems that these families live in.

Future research needs to further investigate how families living with parental mental illness experience family interventions. Knowledge and understanding of how families experience interventions are of great value for professionals in the services that can provide these interventions. Further on, to investigate factors that can enhance the resilience in the families are of importance for research.

It is also important to further investigate how different kinds of family constellations can and need to be supported in family interventions, and to investigate the needs and the support of family members that are often left without support in the care system, such as the partners.

Qualitative studies concerning how families experience family interventions need to be combined with quantitative studies, where the family work in the psychiatric and social services can be followed up.

There is, moreover, a need for further studies where children of various ages can participate in order to increase the understanding of their needs and to develop support programmes for these children.

# POPULÄRVETENSKAPLIG SAMMANFATTNING

Barn som växer upp med en förälder som har en psykisk sjukdom kan få egna problem. De kan till exempel få svårigheter med relationer eller utveckla egen psykisk ohälsa. Alla barn behöver dock inte drabbas. Barn är beroende av sina föräldrar och när en förälder har en psykisk sjukdom kan föräldern ha svårigheter att tillgodose barnets emotionella och fysiska behov. När barn intervjuas framkommer att de behöver kunskap om föräldrarnas psykiska sjukdom och stöd. Uppmärksamheten kring barns situation har ökat väsentligt de senaste åren och har även inneburit att barnens behov av information, råd och stöd har lagstadgats i hälso- och sjukvårdslagen. Familjeinterventioner har utvecklats för att förebygga psykisk sjukdom hos barn och öppna en kommunikation om den psykiska sjukdomen i familjen, vilket har visat sig ha effekt i familjerna.

Avhandlingens övergripande syfte var att belysa hur barn till en förälder med en psykisk sjukdom blir föremål för familjeinterventioner i psykiatrisk vård och inom socialtjänsten, och hur familjer uppfattar detta stöd. I avhandlingen ingår fyra delstudier, varav en är en registerstudie och de resterande tre är intervjustudier med både professionellt verksamma och familjer.

I den första delstudien var syftet att undersöka hur behandlare inom två vuxenpsykiatriska öppenvårdsmottagningar arbetar med familjer med barn under 18 år. Studien undersökte också i vad mån behandlarna identifierade patienter som var föräldrar till minderåriga barn och behandlarnas attityd till att stödja familjen och barnen. 24 behandlare intervjuades, 19 personer deltog i fokusgruppintervjuer och fem behandlare intervjuades individuellt. Resultatet från studien visade att behandlarna balanserade mellan att skapa och upprätthålla en behandlingskontakt med patienten samtidigt som de också behövde undersöka om patientens barn kan vara i behov av stöd. När det gällde att börja prata

om barnen och föräldraskapet i behandlingen anpassade sig behandlaren till patientens situation. I vissa fall kunde det innebära att behandlaren valde att inte prata om barnen för att inte förvärpa patientens psykiska hälsa. De ville inte heller väcka frågor om barnen som kunde upplevas som integritetskränkande. Behandlarna upplevde också att det var ett dilemma att bjuda in barn och partner i patientens behandling, då information om patienten eller till de anhöriga kunde vara komplicerat att hantera i samtalet. Behandlarna uppgav att de själva saknade adekvat utbildning för att arbeta med familjer och barn, men att det fanns andra inom kliniken som var utbildade i familjearbete som de kunde hänvisa till. Familjen kunde även remitteras till en annan vårdinstans. Behandlarna beskrev vidare att de var uppmärksamma på varningssignaler om att patientens barn kunde behöva stöd. När familjer skulle bjudas in i samtal så krävdes det att behandlaren var flexibel och hade kunskaper om barn i olika åldrar och behov. Samarbete med socialtjänsten kring barn och familjer var svårt, både att etablera och att skapa tid för.

I den andra delstudien undersöktes socialsekreterares erfarenheter av att arbeta med familjer och barn när det finns en förälder med psykisk sjukdom. Studien omfattade två socialtjänstverksamheter i två kommuner i Skåne som arbetar med barn och familj. 13 socialsekreterare intervjuades, varav nio deltog i fokusgruppintervjuer och fyra socialsekreterare intervjuades individuellt. I intervjuerna framkom att socialsekreterarnas övergripande uppgift var att se till barnets behov. De strävade efter att stödja barnen och att involvera dem i deras arbete med familjen. Familjer med en förälder med psykisk sjukdom bedömdes på samma sätt som alla andra familjer och gavs samma möjligheter till stöd. Kunskapen om psykisk sjukdom och dess inverkan på barnen varierade bland deltagarna och när barnet inte visade på ett problematiskt beteende så valde man att inte ingripa. Socialsekreterarna var tydliga med att deras uppgift var att stödja föräldern i föräldraskapet men när förälderns psykiska sjukdom blev för svår för föräldern att hantera så misslyckades socialsekreterarna med att nå fram med sitt stöd. Ibland sökte föräldern själv psykiatrisk vård, men i vissa fall så var föräldern inte motiverad till detta eller i för dåligt skick för att göra det själv. Socialsekreterarna försökte då samarbeta med psykiatrin men de upplevde ofta att psykiatrin inte bedömde förälderns behov av vård på samma sätt som de själva gjorde, vilket innebar att de fick ta ansvar för både föräldern och barnet. I dessa situationer upplevde socialsekreterarna att de åsidosatte barnets behov.

Den tredje delstudien undersökte om patienter med minderåriga barn erbjuds barnfokuserade insatser inom vuxenpsykiatrin och om dessa familjer också är involverade i samverkan mellan vuxenpsykiatri, socialtjänst och barn och ungdomspsykiatri. Ett ytterligare syfte var att undersöka om insatserna som

gavs var relaterade till patientens kön, huvuddiagnos, komorbiditet och om patienten varit vårdad inom slut- eller öppenvård. För att följa intentionerna i lagstiftningen har Psykiatri Skåne implementerat riktlinjer Psykiatri Skåne har implementerat riktlinjer om hur de psykiatriska verksamheterna ska beakta barns behov när en förälder är psykiskt sjuk. Undersökningen utfördes med hjälp av registerdata från Psykiatri Skånes journaldatabas och är en totalundersökning. Av de 29 972 personer som var registrerade 1 juni 2014 som patienter inom psykiatri var 3863 (12,9%) personer registrerade som förälder till minderåriga barn. Andelen patienter med registrerade barn var större bland kvinnorna än bland männen. Patienter med huvuddiagnos hyperaktivitetsstörningar, ångest och stressreaktioner och personlighetsstörningar hade fler barn registrerade, medan patienter med schizofreni/psykos och missbruk hade färre barn registrerade. En fjärdedel av patienterna med barn hade fått någon barnfokuserad insats, och av dessa patienter var 13% involverade i samverkan. Om patienten hade fått en intervention fokuserad på familj och barn inom vuxenpsykiatri, var sannolikheten för samverkan med andra stödsystem mer än fem gånger större än om vuxenpsykiatri inte hade genomfört en barnfokuserad intervention i familjen.

Den fjärde delstudien undersökte familjer där en förälder har en psykisk sjukdom och kontakt inom vuxenpsykiatri som omfattar familjeintervention. Hur upplever dessa sin situation och hur har familjen inklusive barnen upplevt familjeinterventionen. Fem familjer blev intervjuade med både familjeintervjuer och enskilda intervjuer. Familjerna berättade att de strävade efter att leva ett så normalt och vanligt liv som möjligt. Både den psykiskt sjuka föräldern och partnern var angelägna om att barnen inte skulle bli drabbade. Partnern och barnen upplevde att de anpassade sig till föräldrarnas psykiska tillstånd och försökte stötta och hjälpa till för att förbättra situationen hemma. Den psykiskt sjuka föräldern hade i perioder svårt att hantera sin sjukdom. Detta ledde till konflikter och stress i hemmet med följden att föräldern kände skuld över sitt beteende och ville att barn och partner skulle få information om den psykiska sjukdomen. Barnen kände sig oroade och förstod inte varför föräldern betedde sig så. De familjeinterventioner som erbjudits familjerna var familjesamtal alternativt föräldrastödsgrupp och barngrupp. Familjerna uttryckte att de var nöjda med att få stöd från vuxenpsykiatri, då de fick hjälp med att hantera föräldrarollen. Detta bidrog bland annat till mindre konflikter i hemmet, och barnen berättade att de kände sig något mindre oroade för föräldrarnas situation, vilket bidrog till att barnen kunde prata hemma om hur föräldern mätte och kunde umgås med kompisar.

Resultaten från studierna visar att vuxenpsykiatrins traditionella arbetsätt, med företrädesvis individuell patientbehandling, kan bidra till att föräldrar med minderåriga barn inte får det stöd som de behöver när det gäller barnen. Dessutom visade det sig att få föräldrar blir identifierade och erbjuds barnfokuserade insatser. Den form för samverkan som förekom mellan vuxenpsykiatrin och socialtjänsten innebar svårigheter för de professionellt verksamma, och det bidrog till att stödet till barnen uteblev eller blev otillräckligt. Föräldrarna och barnen upplevde stödet från vuxenpsykiatrin som positivt och uppskattade att få hjälp med att prata om vad den psykiska sjukdomen medförde i familjen.



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# APPENDIX

## APPENDIX 1

Rolf is a 40-year-old married man. He seeks emergency psychiatric care for anxiety with suicidal thoughts. He has not been feeling well during a long period of time; he has been low and irritated. Sometimes he has been drinking too much alcohol. Rolf believes that his wife has an extra-marital affair, since she is not at home as much as before. He has tried to confront her with his suspicions several times, which has resulted in loud quarrels, and as a consequence his wife has left home for several days on end.

Rolf has been in psychiatric inpatient care but has now been allowed to go home on leave. He is on antidepressive medication and is gradually feeling better. He shares his home with his wife and two children, a 12-year-old girl and a 16-year-old boy.

## **APPENDIX 2A**

### **Interview guide to focus group discussion**

- How would you work with a family like this?
- Do you use any particular family method or intervention?
- What kind of factors influence your decision to involve the patient's family in the treatment?
- What determines if the family is invited to a family session?
- What are the barriers for inviting the patient's family to a family session?
- What characterizes those barriers? Who raised them?
- Do you have any support from your workplace if you want to work with families?
- How would you like to work with families if the circumstances were different?

## **APPENDIX 2B**

### **Interview guide to individual interviews**

- When you meet your patient's family, how do you usually proceed?
- Under what circumstances do you invite the patient's children and family?
- Do you use any particular method or intervention?
- What kind of factors influence your decision to involve the patient's family in the treatment?
- What determines if the family is invited to a family session?
- What are the barriers for inviting the patient's family to a family session?
- What characterizes those barriers? Who raised them?
- Do you have any support from your workplace if you want to work with families?
- How would you like to work with families if the circumstances were different?

## **APPENDIX 3A**

### **Interview guide to families**

- What was the situation in the family when a family intervention was proposed?
- When did you receive the invitation and how did your family react to this proposal? Who brought up the idea of a family intervention?
- How did you decide to participate? Did all family members want to join the family meeting? If not, did you speak about it?
- How did you find the family intervention?
- Have you noticed any changes at home after the intervention?
- Did you discuss the family intervention at home?
- How are things going now in the family?



## **APPENDIX 3B**

### **Interview guide to family members**

- How do you find it living in this family?
- How did you react to the family meetings?
- Did you receive any help from them?
- How did you find out that you were invited to a family meeting?
- Could you understand why you should participate?
- Did you have any expectations about the family meetings?
- How is your family doing now?



## **PAPERS I – IV**



I



## Research Article

# How Adult Psychiatry Professional's View Children

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**Abstract**

**Background:** Children of parents with a mental illness need support from adult psychiatric services. Efforts have been made to enhance the knowledge of practitioners in this field so that they may work in a more family-oriented manner and to include children in the therapeutic services they provide.

**Aim:** This study investigates how adult psychiatry services works with families and children when a parent has a mental illness.

**Method:** Twenty-four Swedish professional care providers were interviewed individually or in focus groups. Data was analyzed using an inductive content method.

**Results:** Although the professionals knew that their patients had minor children, they still prioritized the individual relationship they had with the parent. Few efforts were made to include both children and families in the treatment offered, and when this happened it was done at the professional's own discretion.

**Conclusion:** Despite the mandatory Swedish obligation to pay attention to a patient's children, our study showed that professionals tend to fall short in this regard. Adult psychiatry services needs to strengthen family-oriented work in order to provide support to such children.

**Keywords:** Minor children; Parents with mental illness; Adult psychiatric services; Family therapy

## Introduction

Approximately one-third of patients admitted to inpatient psychiatric care with a mental illness have minor children [1-3]. A parent's mental illness impacts other family members, including their children. The latter are especially vulnerable as they depend on their parents for their upbringing. These children have to deal with the implications of their parents' mental illness in their daily lives [4,5], although parents can have difficulties in talking about their illness with them [6]. Seldom are children included in discussions about the illness between the parent and professionals from psychiatric services [3].

According to research, growing up with a parent with a mental illness constitutes a risk factor [7-9], especially with regard to children developing their own mental health problems [10,11]. Children themselves have expressed the desire to know more about their parents' illness [12,13]. Furthermore, children often assume considerable responsibility in taking care of their parents [13-15], and it is not uncommon for children to perceive themselves as being a cause of their parents' mental illness [16,13].

There is increasing evidence of positive effects that results from treating families in accordance with a systematic model when a parent has a mental illness [17-19]. When children can conceptualize their parent's mental illness as something separate from themselves, resilience increases [20]. In order to realize this important step for children, professionals can use interventions that focus on meeting the needs of children as well as their parents [21]. Still, research has identified a number of difficulties that arise when adult psychiatric services works with a patient's family, including not identifying the patient as a parent, the absence of policy guidelines and a lack of skill

in doing family work [22-25].

In Sweden, professionals in psychiatric services have several mandatory obligations to pay attention to minor children in households where a patient may have a mental illness. The first of these is the obligation, according to the Social Services Act, to report to Social Services if the child is in need of protection, that is, if professionals suspect mistreatment or neglect [26]. The second is to assess the child's need for information, advice, and support, as regulated by the Health and Medical Services Act [27], in cases where a parent suffers from a mental illness. Involving a patient's children and family into treatment requires family-oriented work [24].

In the south of Sweden where this study took place, the management of Psychiatric Services has attempted over the past 15 years to incorporate a child's perspective into adult psychiatric therapy by having a children's representative at every unit [28]. They are responsible for attending to the situation of mentally ill parents with children as well as supporting other colleagues who are treating such patients. For the latter task they have conducted in-service training on child development and the special needs of children whose parents have a mental illness. Psychiatric services management has also supplied compliance guidelines corresponding to the relevant Swedish child assistance laws. They indicate procedures for identifying and supporting patients and their children by increasing the use of models like the Beardslee Family Intervention [29] and Let's Talk about Children [30]. The objective of these interventions is to initiate open communication about parental mental illness within the family, as well as prevent mental health problems for the children of that family. The administrator in the Psychiatric services office is responsible for implementing these guidelines.

When professionals in adult psychiatry adopt a more sensitive approach and invite the parent's family and children to participate in the treatment, such benefits as reduced family burden and improved relationships within the household can be achieved [18]. However, the attitudes of professionals towards including a patient's children in adult psychiatric care are complex. Mayberry and Rupert found that some workers believe the patient's mental illness would increase if family was invited into the therapy or the relationship with the patient might be disrupted [24]. The professional's role and prior training may also influence their attitude about working with families [31].

The aim of this study is to investigate how professionals in adult psychiatric outpatient services who work with affective disorders deal with children and others in the family when a parent has a mental illness. We also examined the way professionals identified parents with mental illness and their attitude towards supporting both the families and the children.

## Material and Methods

### Design

Specialist psychiatric care in the south of Sweden is subdivided into special clinics that provide inpatient and outpatient services within a given region. Professionals were recruited from two adult psychiatric clinics that treat people with affective disorders. One clinic was responsible for the psychiatric care of individuals with affective disorder in a catchment of 130,000 inhabitants. The other unit covered a smaller municipality with 32,000 inhabitants. Both clinics participating in this study had almost a similar organization: an outpatient unit with interdisciplinary treatment teams made up of psychiatrists, psychologists, social workers, nurses and physio- and occupational therapists, with all members of the team responsible for the treatment of patients in the services. Treatment mostly consisted of medical intervention and individual therapy.

In order to explore how professionals work with children and families we collected data in two ways: through focus group discussions and by conducting individual interviews. Focus groups are group discussions [32,33], while the aim of individual interviews is to obtain a participant's interpretation of a specific phenomenon [34,35]. Focus groups promote the study of mutual experiences and identities but when topics are sensitive or hindering factors such as hierarchical professional barriers exist, a combination of both approaches may be useful [36].

The head of one psychiatric outpatient service recommended eight practitioners, whom had shown an interest in child and family work, for our study: four participants for interviews and four for a focus group. A contact person chosen by the head of the other unit suggested two interdisciplinary team members and a group with social workers for the study. Sixteen professionals were recruited in all: 15 participated in three focus groups, and one was the subject of an individual interview.

### Procedure

Four focus group discussions and five individual interviews were conducted. Both the focus group discussions and the individual interviews were semi-structured, using questions like: How do you work with parents? When and if you meet families, do you have a

specific method? What are the factors that make you invite the children and families to participate together?

The interviews lasted from 36 to 85 minutes (mean time: 59 min). They were conducted by the first author, who led the focus group discussions as well, the latter with the support of the second author. The interviews all took place at the psychiatric units. To encourage the participants to engage in the discussion, the focus groups began with the presentation of a vignette. It described a married father suffering from anxiety and suicidal ideation living with two minor children (a 12-year-old girl and a 16-year-old boy). The father suspects that his wife is having an extra-marital affair. This results in loud quarrels and ends with the wife leaving the house for several days. The father has been in psychiatric inpatient care but has now been allowed to go home on leave. The initial question posed to the group was: "How would you work with a family like this?". At the end of the session, each participant had the opportunity to present a short summary of the discussion in accordance with Wibeck [37].

### Participants

In total, 24 individuals participated in the study: 5 participants in individual interviews (3 women, 2 men) and 19 (16 women, 3 men) in a total of four different focus groups, made up with 4 to 6 people each. The participants belonged to different professions: 9 social workers (one also worked as a manager), 5 psychologists, 5 nurses, 2 physiotherapists, 2 psychiatrists, and 1 occupational therapist. Their average age was 52, and the length of time they had worked in their profession ranged from 4 months to 40 years. The vast majority had had some form of therapeutic education, and 7 persons held graduate degrees in psychotherapy, with specializations in psychodynamic therapy, cognitive and behavioral therapy, and family therapy.

### Analysis

The analysis of the individual interviews and the focus group discussions was summarized and the findings presented together. An inductive content analysis concentrating on manifest content guided the analysis since the study had an explorative approach [38]. All interviews were recorded and transcribed verbatim by the first author and names were coded to assure anonymity. Each interview was closely read, reread, and listened to on audiotape several times [34]. An open coding was made in which notes related to the aim of the study were collated. Preliminary categories were formed in order to describe the data and were compared with the transcribed material for confirmation. Categories were grouped to provide a more comprehensive view of the material, and then dichotomized into two main categories. All authors collaborated in this process through a number of discussions and revisions.

### Ethical considerations

Participation was voluntarily, and all informants were assured that they could withdraw from the study at any time. Oral and written information was distributed in advance, and an informed consent form was signed prior to the interviews. The study was approved by the Regional Ethics Review Board in Lund (Dnr 2013/137).

## Results and Discussion

Two main categories resulted from the analysis: 1) establishing a trustful relationship with the patient, and 2) fulfilling legal obligations



towards the child. All participants spoke of coping with the tension between these two categories.

### **Establishing a trustful relationship with the patient**

Subcategories were as follows: a) establishing a care relationship, and b) protecting the care relationship.

**Establishing a care relationship:** It was important in the initial stages of a contact to “create some kind of attachment”, that is, an alliance with the patient. As one of our participants described it, “Sometimes you are more forthright and sometimes you are more cautious, depending on how you perceive what this person can tolerate; and as in all psychotherapy, you don’t jump straight in because first you try to create an alliance, and then gradually you can be more forthcoming”.

Many interviewees described the relationship between the professional and the patient as a process in which the patient was in a defenseless state and in need of trust in order for the contact to be productive. Questions about the family or children were not considered appropriate unless there was a particular issue that attracted the professional’s attention. Some described how inviting the patient’s family to join a session could create a dilemma, i.e., concerns about sharing information about the patient with family members, and how information about the patient provided by family members could negatively affect the relationship of the patient with the professional.

**Protecting the care relationship:** The interviews showed that professionals weighed attention they gave to their patients’ children against the importance of maintaining their own relationship with the patient. In some situations our informants said they wondered how such children coped with their situation; but although they noticed it, they took no action, as when they were trying to convince the patient accept treatment, and at the same time the patient’s children needed support. Some participants assumed that a patient might be upset or feel insulted by questions concerning parenthood and children; and if the informant suggested contacting Social Services, on behalf of their children, it might increase the parent’s level of stress. Some of the interviewees believed that a short period of mental illness would not affect the children, and so children should therefore not be included in the treatment. One commented: “There are many who want to keep things for themselves, and I think this should be respected, even though there can be limits if children are involved. If you’re affected a lot... and you think that there’s a problem in the relationship with the child, then it’s important. You have to weigh each case on its merits”.

Our informants stated that there generally was little direct contact with the patient’s family or children. They stressed the importance in their view, that patients be given individual treatment, and how this could, in fact, could benefit the children. “One helps the children indirectly. By helping the father and the mother through psychotherapy, you unburden them of their inner conflicts, which give them more time for their children”.

The interviewees reported feelings of inconvenience and unfamiliarity in inviting and working with the patient’s children and family. Some of them had skills in family therapy and family interventions, but they seldom used them. However, a knowledge about family work helped them think and deliberate in a more systematic way when treating patients: “I allow myself to use my

theoretical thinking to put the patient in their wholeness”.

The participants described being aware of the child’s perspective, but they lacked the knowledge of what it meant in practice. Some saw it as a demand from the organization and not something that they themselves wanted to do. They assumed that other members of the interdisciplinary team were more qualified in that area than they were.

### **Fulfilling the obligations towards the child**

This category reflected the interviewees’ experiences of taking a family-focused approach when meeting a parent with a mental illness who had minor children. Subcategories were as follows: c) looking for warning signs, d) inviting the children and families needs flexibility, time and collaboration.

#### **Looking for warning signs**

Those we interviewed were conscious of the patient’s children and their obligations toward them when they met with the patient. This was expressed in terms of “warning signs” that could appear for example, when a parent had severe mental illness combined with “situations where the adult uses the child as a parent.”

In situations such as these, the interviewees listened closely to what was said about the relationship between the parent and the child and how the atmosphere in the home was perceived. The informants assessed the patient’s overall situation and considered such factors as their socioeconomic status, and whether or not the patient had a healthy partner or was a single parent. These assessments were conducted throughout their therapeutic contact with the patient.

#### **Inviting the children and families needs flexibility, time and collaboration**

Only a few of the interviewees started their treatment sessions by proposing that the patient bring the family and the children to next session. However, most families stayed away, and those who came could show up at the next session or unannounced. In these cases the professionals assumed that the family was ambivalent about coming. Other informants made their own assumptions when inviting children and family. These were situations such as a patient’s suicide and the wish to support the family members; or when the practitioners noticed that the patient’s handling of their mental illness was overwhelming family life. Some of our informants had their own recollections of growing up with a parent who had a mental illness. Several of the informants turned to social workers on the interdisciplinary team for guidance when discussing whether to invite children and family members to be a part of the treatment plan before asking the patient about it.

When children and families were present at a treatment session, our informants said that they had to spend a great deal of time motivating the patient to involve their family members. Some patients were reluctant to have them there, and as the therapy continued the informant postponed the invitation. Flexibility was required, both when the family suddenly appeared at a session, and when other treatment rooms were required to accommodate all of them. The interviewees described their hesitancy when providing information or simply talking to a patient’s children, depending on how old they were and to what extent they should be involved in the parent’s treatment.

Having family sessions was more time consuming than individual treatments, and those informants who invited families felt that they did not achieve the organization's requirement that they see a certain number of patients each working day. "Of course that's something one says, that we should take the children's perspective, that we should think in terms of the family. That's right, but then there's the harsh reality, which is something else".

Collaboration with Social Services or the Department of Child and Adolescent Psychiatry was described as rarely taking place and difficult to establish:

I think that during the last ten years that I've been working here I've been the one who has invited them most often, so, on the contrary, they are really bad at doing it [initiating contact with adult psychiatry], both from the child and psychiatry unit and social services; it is beneath contempt. They seldom phone and invite us in; it's always me who invites them for collaboration meetings or what's it called networking.

A problem with collaboration was to find the time to meet, since the professionals' schedules were fully booked. If collaboration was necessary and no time was available to arrange a meeting, then the informant was forced to cancel a session with a patient. The interviews emphasized the dilemma of having to ask a patient to forego their treatment session and reschedule the appointment.

Almost all informants in our study underlined the importance of building a trusting relationship with the patient before talking about the patient's children. In accordance with earlier studies [28], our findings also showed that while the professionals knew that the patients had minor children, the children were not necessarily involved in therapy. Even if guidelines specified that involving the patient's children and family in treatment was obligatory, our informants used their own discretion in dealing with this issue. They said that they tended to focus on the individual patient and exclude the patient's role as a parent, in agreement with Fudge et al. [39], although Wang and Goldschmidt [40] have shown that when parents are invited to talk about their children, they want to do so. Few of the professionals we interviewed were active in inviting children and families, similarly to other recent studies. Maybery and Reupert [23] showed that lack of time to work with families was often a hindering factor, and that it was expected that only the social worker on the interdisciplinary teams was expected to initiate contact with Social Services and conduct family-oriented work [25], which we also found. The most common response from our interviewees when we asked them about taking an active role in the needs of the children was that it was not considered part of their assignment.

Some of our interviewees feared that involving children and family could affect trust and confidence in their relationship with the patient in individual therapy, in accordance with the findings of Oppenheim-Gluckman et al. [41]. Although establishing a care relationship with a patient requires confidentiality [42] and protecting the "best interests" of the patient [43], these considerations may also act to seclude the patient's family. In everyday life, people are part of a family and depend on each other [44]. In some cases confidentiality must be breached in order to protect others (i.e.; children). Such decisions depend on the individual professional's attitude and the situation,

as was stated in our study. This leaves the professional in a complex and high-responsible position [45]. However, families relationships are themselves complex issues that generate ethical considerations prior to the start of therapy [46]. Research on psychiatric patients' experiences of involving family members in treatment reveals that they do want them to be invited [47,48].

When children whose parents have mental illness are included in family therapy, they express to be heard during therapy [49,50]. Several interviewees in our study said they seldom invited children or family members into treatment sessions. Instead, they instead they handled the situation by talking with the patient about them during psychotherapy. Moreover, Korhonen et al., [31] found that professionals in psychiatric services who are trained in family-oriented care have been shown to have increased interaction with the children of their patients. Although some of the interviewees in our study were family therapists, they avoided working with children because they felt uncomfortable doing so and seldom practiced in that area, as has been shown in earlier studies [51-53].

Even if the professionals in our study did not meet the children, they did describe of listening for signs that those children were in need of support or protection. When warning signs were noticed, they did not always act upon them, depending on how the relationship with the parent was developing. Brunette and Dean [54] propose that warning signs be used as a therapeutic tool. They urge clinicians to talk to the patient about their concerns and the need to report them, and play an active role in collaboration with Social Services in helping to explain mental illness and its impact on parenting. By doing this in a respectful way, the clinician's alliance with the parent might not be disrupted. Our findings, that practitioners more often pay attention to warning signs than they do provide information and support to children and families, were also found in a study by Liang and Falkov [55].

Our informants noticed that mentioning contact with Social Services to their patients brought about increased stress. Other studies reveal that patients avoid talking about their children because they fear losing custody [56,57]. One study by Bournsnel [58], indicates that parental mental illness is viewed in stereotypical way in social work, and is often stigmatized as a risk factor for child protection, as another study confirms [59]. Earlier studies have also shown that families suffering from a parental mental illness differ in their need and for support [54], just as families in general. Providing families with individualized support that involves family members in collaboration with both the formal and informal network has been proven to be effective [60].

Collaboration with other actors was rarely mentioned in our study. It was expected that the social worker's role, within the psychiatric services organization was to initiate contact with Social Services and conduct family-oriented therapy, as seen earlier by Slack and Webber [25].

It is known that family involvement has a positive impact not only on a person suffering from mental illness and that person's children [29]. Children involved in family interventions reveal increased knowledge of their parent's mental illness and fewer concerns about them [61]. Studies indicate a growing willingness on the part

of families and professionals to include families in adult psychiatry [46,62], although establishing this perspective is a slow process [18], as our study confirms. Needed are the systematic implementation of family work and the child's perspective [22], resources for broadening the therapeutic approach through the use of structured models [63], and flexible ways to handle confidentiality. Although the central concern for professionals is establishing a trusting relationship with the patient, family-sensitive work also has obligations to fulfill towards children. Today parents with mental illness are more involved in their children's lives than twenty years ago, as advances in psychiatric treatments and deinstitutionalization enable patients to handle their mental illness outside hospitals [64]. In order to assess whether a patient's children need supportive or protective social services, family relations have to be talked about as apart of treatment and should not be dismissed out of hand by invoking confidentiality [44].

#### Methodological considerations and limitations

The professionals who participated in our study were recruited by staff leaders in adult psychiatric clinics and not by random selection, which might indicate that participants were chosen because they had a special interest in the issue. However, an effort was made by the authors to include all the professions working on an interdisciplinary team. Since we wanted the focus groups to provide us with information from everyday treatment situations, we chose participants who were already known to each other, in accordance with Kitzinger's advice [65]. However, we cannot be certain whether the focus group discussion created this open atmosphere, or if the informants in the focus groups were in a vulnerable position because the interviews we conducted related to matters of how professionals handled a mandatory obligation. After some of the focus group discussions, informants said the discussion was thought-provoking and important. Even if individual interviews allowed participants to say what they thought, uninfluenced by the presence of other participants, we do not know whether our participants did this, since the interview situation is related to context and communication [66].

There are some limitations in this study. First, all the professional groups providing psychiatric services were not equally represented in the focus groups (two of the focus groups consisted of only social workers and a nurse). Furthermore, the first author has worked for many years in adult psychiatric services, and this which could have had an impact on the data analysis. Discussions with the other two researchers were carried out during the different phases of the analysis in order to counteract the possible effect of the first author's pre-understanding. The data gathering could have been accomplished by other methods, such as by observing an interdisciplinary team or studying case material in medical journals. This was not possible due to the project's restricted resources.

#### Conclusion

Although the obligation of paying attention to a patient's children is mandatory, many of the informants in our study did not fulfill this obligation. Instead, the informants focused on building a trusting relationship with the patient in place of talking about and to the patient's children. Although the process of implementing a child perspective in adult psychiatry has been going on for almost two decades, greater efforts must be made if professionals are to work in a more family-sensitive and child-oriented manner. Children in

families where a parent has a mental illness have the right to be heard and supported by psychiatric services. This is an issue that must not be overlooked by professionals. By combining family-sensitive work with individual therapy on a regular basis, children whose parent is living at home with a mental illness will have their rights better served.

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III



# Children of Parents With Serious Mental Illness: The Perspective of Social Workers

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The aim of this study is to describe the experiences of children's social workers in Sweden who work with families in which a parent suffers from serious mental illness, and how a child in such a family receives support. Data were collected through individual interviews and focus groups discussions with 13 professionals in 2 minor municipalities in southern Sweden. Interviewees stated that parental serious mental illness was not a main focus for children's social workers. When parental serious mental illness became a barrier to caring for their children, the children's social workers sought to collaborate with psychiatric services, but in many cases it did not turn out well. Providing support to the parent was one way of aiding the family, although at the price of setting the child's perspective aside. Being faced with responsibility for the parent and the child left children's social workers feeling they were the last outpost for the families. Children's social workers require greater knowledge of how to handle parental serious mental illness, and more interagency collaboration with psychiatric services is needed to adequately support children of parents with a serious mental illness.

*Keywords:* children of parents with serious mental illness; parental serious mental illness; children's social workers; psychiatric services

## Introduction

The ability of parents to cope with their family responsibilities is affected by a serious mental illness (Newman et al. 2007; Wilson and Crowe 2009). In families with a parent who has a serious mental illness (SMI), children are often in need of extra support. The child of a parent with an SMI is a risk factor for developing own psychological problems (Barker et al. 2012; Rutter and Quinton 1984). However, not all children suffer such adverse effects (Falkov 2014). Psychiatric services offer various medical, psychological or social interventions for patients and their families. In Sweden, children's social care services have to be involved in order to protect the child and support the family (Social Services Act, SFS 2001:453, § 5:1).

A parent's SMI can consist of preoccupation with their own condition, a lack of energy, or unpredictable behaviour (Trondsen 2012). Such expressions can be difficult for the child to understand and endure (Garley et al. 1997; Knutsson-Medin, Edlund, and Ramklint 2007). Studies (Ostman 2008; Stallard et al. 2004; Trondsen 2012) examining a child's experiences when a parent has an SMI reveal that some children take great practical and emotional responsibility for the parent, whereas they may themselves lack support (Falkov 2014). These children have a desire to communicate both with their parent about the illness, and also with their other, healthy parent or someone in their social network in order to be reassured that they are not responsible for their parent's illness. Moreover, children in such families may live in fear for the parent's mood changes, particularly regarding suicide. Some children in these families are obliged to act as caregivers for their parents, a responsibility which, if it is unsupported and inappropriate to the child's age, can have a negative impact on their development and overall childhood (Aldridge 2006).

Swedish social services bear the responsibility for providing children with support and protection when their parents lack the ability to act as their children's custodians. The Social Services Act has sections dealing with support, compensation and control (Ostberg 2010), as modified for different communities. On the basis of applications from welfare agencies, families, individuals and outreach services, children's social workers assess the need for support and protection for families in which a parent has an SMI. Such support can consist of parenting programmes, family counselling or placing children in foster homes during a period of crisis (Hansson 2004). Social workers often begin their careers in Social Services without special knowledge in psychiatric care (Dellgran and Höjer 2005). However, the Bachelors of Social Work programme in Sweden provides broad opportunities for choosing areas of mental health in their specialisation (National Agency for Higher Education [Högskoleverket] 2003).

In Sweden, the provision of adult mental health care is organised into sub-specialised psychiatric services with catchment area responsibility. All psychiatric service professionals have a mandatory obligation to give their attention to a patient's children under the age 18. If professionals suspect maltreatment, they must report to social services that they believe that the child needs protection (SFS 2001:453, §14:1), and they have to assess the child's need for information, advice and support (SFS 1982:763, §2g). Judging a patient's need for support with children, and whether those children might be at risk, can be a complex and stressful decision, depending on the professional's role, working culture and one's own feelings (Rouf, Larkin, and Lowe 2011).

The need for collaboration and interagency work on behalf of children whose parents have an SMI has been stressed in recent decades (Darlington, Feeney, and Rixon 2005; Hetherington and Baistow 2001). While interagency collaboration is an effective practice, several studies have shown that it can also be problematic (Darlington and Feeney 2008; Darlington, Feeney, and



Rixon 2005; Stanley et al. 2003). Barriers such as communication problems, lack of knowledge and skills, and the absence of guidelines supporting collaboration have been reported. In order to improve the situation for families at risk, a whole family approach, in which both child and adult services can work together, is needed. In the UK a 'Think family agenda' is an example of such collaboration (Cabinet Office 2008). In Sweden, health care and social services are obliged to coordinate their support when an individual's needs require it, and together establish a coordinated individual plan to clarify each service's responsibility (National Board of Health and Welfare n.d.-b)

It is estimated both in Sweden and internationally that almost one-third of those in psychiatric in-patient services are parents of children aged under 18 years (Maybery et al. 2009; Ostman and Eidevall 2005; Skerfving 2007). An Australian study revealed that 29% of new child protection applications brought to court concerned children with a parent who had an SMI (Sheehan 2005). In Sweden, there are no such figures available (Wiklund 2008). However, according to Lundström (1996), one-fourth of the reasons children are taken into protective custody is parental SMI.

How children's social care services support such families has rarely been studied, although there are data on working with families with children up to 7 years old in vulnerable situations (Hagström 2009). Some international studies concerning the interface between psychiatric services and social services in different settings indicate that this collaboration needs structured interventions as well as joint educational support (Darlington and Feeney 2008; Hetherington et al. 2002). The aim of our study was to examine the experiences of a representative group of Swedish professionals from children's social care services who provided support to families and children when a parent has an SMI.

## **Methods**

### ***Design***

In order to see how children's social care services professionals work with families in which a parent has an SMI, we created focus groups whose participants could discuss their views and experiences with such families (Kitzinger and Barbour 2001). We also conducted individual interviews in order to be able to concentrate on specific casework phenomena (Kvale and Brinkmann 2009; Robson 2002).

Of seven children's social care services in seven municipalities in southern Sweden that were invited to participate in the study, two units accepted. Each of those municipalities have a catchment area of 15,000 inhabitants, had similar child welfare organisations and are representative of the social workers in Sweden. In order to gather data effectively, we asked the manager of each agency to propose individuals involved in family work. At the first unit five

children's social workers agreed to participate in a focus group, and two in individual interviews. At the second, four agreed to take part in a focus group and two in individual interviews.

### ***Procedure***

In total, two focus group discussions and four face-to-face interviews were held. Both used semi-structured questions and inquired into how participants worked with SMI parents and their children, and whether they used any particular method when meeting with such a family. Each interview lasted between half an hour and one hour and a half. The individual interviews were conducted by the first author, whereas the focus group discussions were led by the first author with support from the second author. All interviews took place at children's social care service centres between June and October 2013.

The focus groups began with the presentation of a vignette to encourage discussion. The story told of a married father who had anxiety attacks and suicidal thoughts. He was living with two minor children, a 12-year-old girl and a 16-year-old boy. The father suspects that his wife is having an extra-marital relationship. There are loud quarrels and the wife leaves the house for several days. The father receives psychiatric in-patient care and is permitted to go home on leave. The initial question to the group was: 'How would you work with families like this?' At the end of the focus group session, each participant had the opportunity to give a feedback of the discussion, following one of Wibeck's four phases (planning, recruiting, discussion including feedback and analysis) in the process when working with focus groups methods (2010).

### ***Participants***

In total, 13 people (12 women, 1 man) participated in the study. The two focus groups each had four or five people, and four people were individually interviewed. The average age of the participants was 44 years (range 29–57) and their experience working in different family interventions varied from 3.5 to 34 years. Eleven were qualified social workers. Of the remaining two, one had a social pedagogy education and one worked as a treatment assistant. One had earlier worked as a social worker in adult psychiatry. Two were also managers. Several participants had additional training in family or group-related methods.

### ***Data Analysis***

Since the study was exploratory (Elo and Kyngäs 2008), we conducted an inductive analysis focused on manifest content, inspired by the naturalistic approach

of Lincoln and Guba (1985). All interviews were recorded and transcribed verbatim by the first author and also coded to assure anonymity. Each interview was closely read, reread and listened to several times to obtain a full picture (Kvale and Brinkmann 2009). Open coding was used to collect notes related to the aim of the study. Preliminary categories were formed in order to begin structuring the data. A grouping of categories was then established to allow more comprehensive classifications, and those classifications were then dichotomized into two main parts. The analysis of the focus group discussions and the individual interviews were then combined. An ongoing discussion was carried out between the co-authors to achieve consensus during the sorting and categorising of the data and at all stages of the analysis. The trustworthiness of our findings is supported by comparisons with previous research in the field in the discussion section, and by quotations from the participants.

### ***Ethical Considerations***

Professional guidance given to parents with SMI can be an area of ethical controversy that must be handled with sensitivity, although many of our informants welcomed the opportunity to talk about this difficult theme. Oral and written information explaining the purpose of the study was distributed to participants prior to the interviews. Informed written consent was obtained and it was made clear that participation was voluntary, and anyone was free to terminate the interview and their participation at any time without having to provide an explanation. In accordance with Swedish regulations governing research involving humans, the study was approved by the Regional Ethics Review Board in Lund (2013/137).

### **Findings**

Our analysis recognised two main categories: (1) Identifying with the situation of the child, and (2) Handling parental SMI when not a specialist worker in mental health.

#### **(1) Identifying with the situation of the child**

This category is divided in two subcategories: (a) supporting the child's needs, and (b) parental SMI is not a children's social worker's main focus.

#### ***Supporting the Child's Needs***

Our informants said that their most important responsibility, the one required by law, was identifying the needs of the child. When a new case arrived at

children's social care services, a method known as BBIC ('a framework for assessment, planning and reviewing in child welfare which provides a structure for systematically collecting information and documenting children's and young people's need of services' [National Board of Health and Welfare [Socialstyrelsen] 2013]) was used to assess the goal for the intervention.

Since the informants usually dealt with families where there had already been a stressful situation for the child, they emphasised that their role was to support the child and not let the child feel betrayed. The children's social workers were concerned not to keep secrets from the child and wanted all interventions involving the children to be transparent. They noted that many children were filled with anxiety and needed reassurance that their parents would get help. This would unburden children from feeling responsible for their parents and strengthen those children. One participant, however, said that sometimes too much weight was given to the child's perspective, and that speaking with parents about sensitive issues should not always include the children.

### ***Parental SMI is Not a Children's Social Worker's Main Focus***

Our informants stressed that parental SMI as such was not the key indication for social services to intervene in the family. Instead they spoke of examining risk and protection factors in order to consider how the SMI of the parent might affect the child. If they concluded that there were risk factors in the family, but those risks were not severe, they assumed that the healthy parent or partner could be responsible for the children. Consequently, the family received no support from children's social care services. As one person expressed it, 'In these cases we put a lot of responsibility on the healthy parent'.

Our interviewees described how they approached parents with SMI in a way similar to other families. They gave such parents the same opportunities to join parent training programmes, family therapy sessions and child support groups as all other families, and their children could also be placed in foster homes if needed. Participants spoke of systemic thinking about families. One informant commented about 'methods like the Komet direct method (a manual-based programme designed to support parents who feel that they are often in conflict with their child [National Board of Health and Welfare, n.d.-a]) and parental education. Otherwise it is mostly about being a role model and learning by doing'.

Those we interviewed told us that children's social workers take into account the severity of a parent's mental health symptoms when judging their impact on children. While a parent's depression might not in itself be considered as serious, when the depression involves suicidal behaviour, the situation is assessed as unsafe for the child. A parent with a psychosis was generally considered more seriously ill than one with depression. If a child

showed no externalised behaviour, our informants reasoned they did not have to intervene.

Children's social workers spoke of having an objective they were expected to fulfil. This seldom included offering psychotherapy just to a parent. Instead, they were to facilitate sessions with the family or both family and child in order to restore a tolerable level of family life and prioritise basic needs. They emphasised the importance of being professional and not succumbing to their own worries and fears about their clients. They had a concept of how family and children should be taken care of, based on their education as social workers, and took pride in their work and their ability to deal with difficult situations.

## (2) Handling parental SMI when not a specialist worker in mental health

In our categorisation of recurring themes in our interviews, the main one referred to addressing the parent's SMI on the one hand, and fulfilling the role of being the child's advocate on the other. This overarching concern was divided into four subcategories: (a) identifying a parent's SMI, (b) losing the focus on parenting, (c) setting the children's perspective aside and (d) collaborating with psychiatric services.

### *Identifying a Parent's SMI*

Our interviewees stressed that their task was not to treat a parent's serious mental illness but support the parent in handling their illness in relation to their parenting role. Some parents were open about their illness, and in a few instances the children's social workers said that they were able to provide assistance to the parent while psychiatric services treated their SMI. This may take the form of collaborating with children's representatives from psychiatric services (Ostman and Afzelius 2011), or with parental support groups. In most cases, however, parents with serious mental issues were not paying sufficient attention to their illness or had problems coping with it. Over time, the parent's SMI grew more obvious and became a barrier to the support children's social workers were trying to provide. The parent complained of fatigue, body pain and worry, and the children's social worker concluded that psychiatric support was necessary for these individuals to be able to function as parents.

We can work ourselves to death with parental strategies or whatever method we choose ... When a parent is in bad shape and needs help ... we are not the ones who can help them. All we can do is to improve the child's situation ... it is to guide the parent to seek their own treatment.

Sometimes our informants found that the parent did not want to discuss their problems for fear of losing their children, or because they had had bad experiences with earlier psychiatric treatment. Some children's social workers

felt that even asking a parent about their SMI was intrusive, especially if the illness was considered short-term, while others considered it a mandatory duty when working with these families.

A parent's SMI sometimes came up in support groups devoted to parenting, or when dealing with parents who filed for divorce and had to work out the children's custody arrangements. Beyond advising the parent to seek psychiatric help, children's social workers were reluctant to intervene in psychiatric matters, considering that if they did, it might be disrespectful to the parent.

### ***Losing the Focus on Parenting***

Several informants said it was difficult for them to understand the parent's SMI and the way it affected them as a parent. Sometimes they felt misled by the parent and what the parent told them about their treatment. As a result they might not know whether the parent required medication or needed continuing psychiatric care. Even in cases when last contact was between the parent, psychiatric services, and children's social workers, and mutually agreed upon decisions were made, our informants commented that parents often had their own agenda and did not follow the joint treatment plan. One participant commented, 'This is a problem when working with some parents, because we do not share the same picture of reality or what was done during the sessions, and this makes it even harder'.

Some parents who were neither interested nor motivated to share information about their SMI with their children's social workers caused the latter to wonder how those parents handled their SMI in front of their children.

### ***Setting the Children's Perspective Aside***

Our informants spoke of critical situations in which they experienced that they had to relinquish supporting the child in order to handle the parental SMI, as when a parent with suicidal tendencies who required inpatient care engaged the informant so completely that there was no possibility of supporting the child; or when a severely depressed parent, assessed by psychiatric services not to be in need of inpatient care, was left at home with children and the children's social worker had to attend to the parent instead of the children. Some interviewees spoke of being overwhelmed by a parent's needs and having to make a choice between the parent and the child. A feeling of deserting the child made some informants conclude that it may not be possible to work on behalf of children while attending to their parents who have an SMI.

### ***Collaborating with Psychiatric Services***

Our informants expressed dismay over their efforts to discuss a parent's SMI with someone at psychiatric services. Such discussions often ended in deadlock, and they either had to follow the psychiatric services treatment plans or take care of the parent and the family by themselves. One informant stated, 'It can be a very frustrating when you try to suggest something and the discussion is cut off before it starts by "We don't work like this"' Participants were sometimes told by psychiatric professionals to place the child in a foster home, rather than collaborating to assist the child. Several of the interviewees stated that psychiatric services disregarded the children and were only concerned with the parents. This led to a feeling of 'being the last outpost' for families and taking upon themselves the responsibility for both the child and the parent. In such situations, children's social workers felt they were unsupported and had to deal with assignments they were not trained to handle. If a coordinated individual plan had been drafted, as is mandatory, it would have facilitated the collaboration; or, as one informant said, 'if we used a SIP [coordinated individual plan], it would work out. Clients should not be caught in the middle, it would be very clear what to do, and there would be no conflict'.

Participants further described the lack of collaboration with psychiatric services and their own limited knowledge of psychiatric diagnosis as giving them a sense of 'not speaking the same language' as those doctors or psychologists from psychiatric services. Some thought that professionals use psychiatric terminology in order to exclude a collaboration, and to show that their tasks differed in many ways. Our informants told of adult psychiatric workers focusing too often on improving a patient's psychiatric functioning as their sole objective. Others spoke of how psychiatric services had been going through changes in response to demands to work more efficiently. Some psychiatric clinics gone into private management, and there is now a lack of psychiatrists. However, a few informants reported good relationships with a children's representative, and wanted to use the knowledge they had gained in family interventions with their own clients. Being able to refer new parents to a support group for depressed parents in a psychiatric unit led to collaboration on behalf of some children. One informant who had positive experiences from working in interagency collaboration stated that 'meeting and getting to know more about each other can be a step further in working together'.

### **Discussion**

Our interviewees discussed the challenge of handling children and families where a parent had an SMI, although they were not specialists in this area. When the parental SMI was either denied by the parent or interfered with their

support of the child, the professionals could not ameliorate the child's situation. Helping the parent to obtain psychiatric support sometimes turned out well, but it also resulted in having to serve the parent's needs instead of the child's.

### *The Role of a Children's Social Worker*

Children's social workers feared that assessing risks and providing support to children might endanger their relationships with parents, who may feel threatened in their ability to parent, stressing a precarious relationship that has earlier been described by Stanley et al. (2003) as requiring trust. As in the study by Sheehan (2005), our interviewees found it hard to identify a parent's SMI. Some parents avoided the issue of their SMI because of bad past experiences with psychiatric services, and because they were afraid they might lose custody of their child (Aldridge and Becker 2003; Diaz-Caneja and Johnson 2004). Children's social workers faced the difficult task of providing support as well as making decisions about the child's safety and placement that might interfere with their relationship to the parent (Stanley et al. 2003). Moreover, the fear of stigma can prevent someone from talking about their SMI (Chang and Horrocks 2006). Stigmatising behaviour towards someone with SMI has even been found in the attitude of some mental health professionals (Overton and Medina 2008), and perhaps among social workers as well.

Our informants spoke of how they tried to identify with children and support their needs. One way was to be transparent with information to both children and families, although one participant thought the children should not be involved in sensitive issues. Thus, this can be a balancing act in which the relationship to both the parents and the child is endangered. However, explaining to children that their parent will get help is reassuring. In contrast to earlier studies, showing that parents with SMI want help in their parenthood as well as support in everyday life including talking to their children about their illness (Benders-Hadi, Barber, and Alexander 2013; Diaz-Caneja and Johnson 2004), our informants did not experience these needs. In addition, family interventions have been shown to reduce the risk of children developing the same SMI as their parents (Siegenthaler, Munder, and Egger 2012).

When our informants described family situations in which they judged that children did not need support, they were making an assumption that the children were unaffected by the parent's SMI. However, under those circumstances the social workers may fail to adequately assess the children's needs, as shown by Cederborg (2014) and Ostberg (2010). Even if the child does not exhibit any externalised behaviour, it cannot be taken for granted that the child has no need of support. Family resources and the nature of the parental SMI must be taken into consideration, as different studies have demonstrated a relationship between parental SMI and disturbances in the child (Oyserman et al. 2000; Rasic et al. 2014).



### ***Supporting Parents with SMI***

Parental SMI and their effect on children elicited different views among our interviewees, similar to the findings of Hetherington and Baistow (2001). SMI can fluctuate, and even if it is a short-term illness, it can be presumed that it might affect the child in some way (Hetherington and Baistow 2001). When collaboration with psychiatric services fails, children's social workers are left to assess the situation on their own, and according to Barbour et al. (2002), they tend to underestimate the severity of the SMI. Our interviewees' emphasis on treating all families alike can indicate a lack of knowledge about SMI and its impact on children.

Our informants also placed a lot of emphasis on the healthy partner when assessing the needs of children within families, where one parent has an SMI. Research into the situation of relatives living with someone with an SMI reveals how vulnerable that position is. A spouse or partner who bears the responsibility for the household and the children, may feel taken advantage of by psychiatric services if they find they have to care for their seriously mentally ill counterpart with no outside help (Ostman 2000; Ostman and Hansson 2004; Tranvåg and Kristoffersen 2008). As a result, the responsibility placed on the healthy member of the household can be overwhelming and the burden may result in such individuals having their own psychiatric problems (Wittmund et al. 2002).

Supporting families through social services can be achieved without having to set aside the child's perspective. Having a family approach, where both parents and children can get help to begin communicating, can give children a better understanding of the SMI, unburden them of the responsibility for the parent, support the parents in the rehabilitation process, and help them fulfil their parenting role (Maybery, Reupert, and Goodyear 2015; Pihkala, Sandlund, and Cederström 2012). Our informants had positive experiences of working with children's representatives from psychiatric services and benefitted from their knowledge of family intervention. Such mutual support could be developed through interagency collaboration.

### ***Collaboration between Social Services and Psychiatric Services***

Interagency collaboration is necessary to support children in families with a parental SMI (Hetherington and Baistow 2001; Stanley et al. 2003). Our informants' experiences convinced them that collaboration was generally unattainable, except in a few instances, where it was obtained through earlier professional contacts. However, those professionals who are in psychiatric services may have their own individual opinion of interagency collaboration with social services. Families in need of support are at great risk if they are dependent for support on an individual professional's interest or disinterest in

collaboration, rather than being provided for by formalised interventions through an organisational structure (Darlington and Feeny 2008). Our results are in contrast to an inter-country comparison by Hetherington et al. (2002) which found that the link between mental health and child welfare services in Sweden was described as uncomplicated. A few of our informants were satisfied with their collaboration with psychiatric services. However, most interviewees complained about psychiatric professionals' lack of time and disinterest in their patient's children. Slack and Webber found (2008) an attitude among mental health workers that this is 'not my role'. Such a dismissive attitude often left children's social workers unsupported in carrying out their duty. Moreover, we found that children's social workers perceived that they had a lower status than doctors and psychologists, as seen in an earlier study (Stanley et al. 2003). In our informants' experiences this lower status was also found to be a barrier to collaboration. Although social workers need the knowledge and expertise from other professionals to make good decisions in supporting families (Levin and Linde'n 2000), little attention is paid to SMI in the bachelors programme for social workers in Sweden, something that could be remedied by changes in the curriculum. Social workers could be trained to better recognise symptoms that children are being affected by SMI in their family and to feel confident to challenge the views of psychiatric professionals about family and child welfare issues within their competence (Bournell 2014). As Ostberg's study (2010) has shown, this should make it possible for them to be aware that a child may need support, even if she or he does not show any overt behaviours or injuries.

Our informants mostly became aware of families in which a parent has an SMI through referrals from psychiatric services or a family's own approaches for help. Psychiatric services often neglect the children of such parents (Korhonen, Vehviläinen-Julkunen, and Pietilä 2008; Maybery et al. 2014), which might result in fewer psychiatric referrals to social services departments. Often only the most severely troubled families are referred to social services through their own applications, but the majority of parents in need never receive any contact (Priebe and Afzelius 2015). Several studies describe problems with psychiatric services that lack skills to provide family therapy, or have limited resources for doing so (Maybery and Reupert 2006; Slack and Webber 2008). In addition, there is the problem of 'silent parents', that is, those in need of parenting support but who hide serious mental illness and receive psychiatric care only when it is urgent (Bournell 2007). Single parents with custody of their children have been shown to wait too long for psychiatric care because they are concerned about their children's placement during a possible hospitalisation (Bassett, Lampe, and Lloyd 1999).

The statutory outreach service; social services' obligation to follow and meet those people in the municipalities which have special needs i.e. children in families with SMI, was never mentioned by our interviewees. According to the Swedish National Board of Health and Welfare (2012), social services should initiate preventive work in collaboration with psychiatric services rather

than leaving the responsibility for the children to the family of a parent with an SMI. However, collaboration requires trust in each other's competence (Darlington, Feeney, and Rixon 2005) and a shared knowledge base (Hetherington et al. 2002) in order to provide family support. To identify parental SMI and intervene early as suggested by Falkov (2014), might prevent ill health in children.

### ***Methodological Considerations and Limitations***

Combining focus group discussions and individual interviews allows both individual views and collective attitudes to be represented in the data gathering. However, although attempts were made to maintain a non-threatening atmosphere in the focus groups, the sensitivity of the issue and workplace hierarchies may have kept some participants silent (Mitchell 2001). Informants may also have felt themselves in an exposed position during the individual interviews because the issue was a matter that could be seen as something they neglected, but actually should be doing, and so they may not have revealed all of their experiences.

There are some other limitations to consider. For a study that aimed to illuminate how children's social workers approach family work in the case of parents who have an SMI and their children aged under 18 years, the number of participants was small, thus limiting the applicability of our results to the municipalities we sampled. Our intention, however, was not to generalise our findings but to describe a phenomenon. Moreover, since our data were self-reported, we are unable to confirm that our informants described what they actually do in practice. Other more resource-intensive methods, such as observational studies or studies of case materials, might have given another picture of children's social workers' experiences. Furthermore, our study examined only children's social workers' viewpoint; other professionals working with families with SMI may have different opinions or equally difficult barriers to surmount in order to practice effectively.

### **Conclusions**

Children in families where a parent has an SMI are vulnerable and often in need of support. Children's social workers in Sweden assume the responsibility for the welfare of children, but when a parent has an SMI, they also have to provide for the parent's needs. A children's social worker's knowledge of parental SMI and its impact on children in the family needs to be improved through the educational system, at both qualifying and post-qualifying level. Moreover, in order to increase knowledge and understanding, both psychiatric services and children's social care services have to develop interagency collaboration using a whole family approach and embracing acknowledgement of

mutual values. Joint educational experiences in family work might be one way to facilitate that. Professionals with specific assignments as children's representatives could build a network with colleagues at other welfare agencies. By using coordinated individual plans, families with SMI can be supported. For that to happen, a multi-faceted approach to whole system change is needed. Also the availability of knowledge of evidence-based intervention for families that include a parent with an SMI, involving good provision of information about adult psychiatry, make it easier for social workers to do their job successfully. These improvements would lead to better collaboration between child social workers and mental health professionals in Sweden.

### Disclosure Statement

No potential conflict of interest was reported by the authors.

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