

# **The experience of the children of patients detained in secure psychiatric settings**

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## SUMMARY

This thesis examines the experience of the offspring of parents who have been detained in secure forensic psychiatric hospitals. Such hospitals accommodate patients who have a major psychiatric disorder who also present a serious risk to others. Offspring therefore experience several adverse childhood experiences.

In the absence of any research literature on these offspring, I conducted scoping reviews on the key facets of such offspring's experience – parental major psychiatric disorder, parental serious risk to others and parent-child separation. A review of systematic reviews was completed regarding parental psychiatric disorder. Outcomes included increased risk of offspring psychiatric disorder and/or behavioural, emotional, cognitive, or social difficulties compared to children of well parents. No review focussed on strengths.

Clinical records were used to examine a 9-year cohort of secure psychiatric hospital patients. Nearly half (46%) of the patients were parents and over half of the children (60%) were under-18-years-old at the time of the parent's admission. Parent-patients were less likely to have diagnostic comorbidity or to have accessed psychiatric care in childhood than childless patients but were more likely to have committed a homicide/life-threatening offence and towards someone known to them. Parent-child contact was examined, finding that under-18-year-olds were more likely to lose all contact with their parent than adult-aged offspring.

Finally, adult aged offspring were interviewed in a qualitative study using Grounded Theory techniques. A core concern of 'chaos and confusion' emerged from the data, but this was resolved through a sense of 'stability, security, and autonomy'. Although a model emerged from the data, data saturation was not reached, and the results must be treated cautiously. Recruitment was challenging and barriers are discussed. Stigma, which presents throughout the thesis is also discussed as well as the risks presented to the offspring related to them having a parent in a secure psychiatric hospital.

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## PREFACE

This is a brief statement to highlight how two papers I have authored and one which I have co-authored relate to my thesis. I will also mention two projects relating to the work in my thesis, which have resulted in poster presentations at conferences, and on which I am a co-author.

In this statement and in the main text of the thesis, I use initials for my PhD supervisors, Pamela Taylor (PJT) and Frances Rice (FR), for my colleague Natasha Kalebic (NK), and for Jennifer Kent (JK) who completed a placement with the department as a medical student.

This thesis includes amended versions of two published papers on which I am first author.

An amended version of the first of these, Argent et al., (2020) forms a major part of chapter 2. The full reference is:

Argent, S.E., Kalebic, N., Rice, F. and Taylor, P. (2020). Offspring outcomes when a parent experiences one or more major psychiatric disorder(s): a clinical review. *Evidence Based Mental Health*, 23(3), pp.113–121.

SA and PJT conceived the work and the review question. SA and PJT together with NK and FR worked on the design of the review protocol. SA and NK rated the first 100 titles and where necessary abstracts of the results generated by the searches. The remaining titles and where necessary abstracts were rated by SA. The full texts which were acquired following rating of the search results were rated by both SA and NK. Where there were any discrepancies, discussion with PJT resolved this. SA completed quality assessment of the reviews which remained after examination of the full texts. Data extraction of the reviews deemed eligible for inclusion was undertaken by both SA and NK. The results from data extraction were examined by all four authors and discussed extensively. SA drafted the work and the three other authors each revised it critically. All four authors gave their approval of the final version submitted for publication and have agreed to be accountable for all aspects of the work and ensure that any questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

The second paper Argent et al., (2017) forms a major part of chapter 3.

The full references is:

Argent, S.E., Riddleston, L., Warr, J., Tippetts, H., Meredith, Z. and Taylor, P.J. (2017). A period prevalence study of being a parent in a secure psychiatric hospital and a description of the parents, the children and the impact of admission on parent-child contact. *Criminal Behaviour and Mental Health*, 28(1), pp.85–99.

The research questions were developed by SA and PJT. The data were collected and entered onto an SPSS database by 3 students, Jodie Warr, Hannah Tippetts and Laura



Riddleston. The database was reviewed by SA and any gaps or discrepancies rectified by SA. SA scored the seriousness of the violence in the index offence and offending histories according to the Gunn and Robertson violence subscales. Data analyses were performed by SA. The work was drafted by SA and critically revised by Zoe Meredith and PJT. All authors gave their approval of the final version submitted for publication and have agreed to be accountable for all aspects of the work.

I am a co-author on four further references relevant to this thesis. One of these is a paper in a peer reviewed journal, one is a PROSPERO registered protocol, work relating to which has also been presented as a poster at the RCPsych Forensic Faculty Conference 2022 (awarded third place), and the fourth is a poster which was presented at the RCPsych International Congress 2021.

The paper I am a co-author on is referenced below:

Kalebic, N., Adams, A., Bezeczky, Z., Argent, S., Bagshaw, R. and Taylor, P.J. (2020). Social workers' perspectives on people parenting while patients in a secure hospital. *The Journal of Forensic Psychiatry & Psychology*, 31(3), pp.364–384.

This paper is referenced in several chapters in the thesis, as the social worker perspective on the patients who are parents within the same medium secure hospital as my empirical work is drawn from, was relevant to the work on which I have led. On the above paper I was involved primarily in data analysis and writing up the paper, but it was Natasha Kalebic who led on these aspects of the work.

The following two references both relate to the systematic reviewing work on the experience of stigma by children who have, or who have had, a parent in prison. The first relates to the systematic review protocol and the second to a poster presentation of this work, but they are both pertaining to the same project. This project stemmed directly from my PhD project work in terms of conceiving the project and I was involved particularly in the early stages, such as developing the title, the research questions and search terms, but Natasha Kalebic has led on taking this forward. Tallulah Thomas led on the compilation of the poster.

Kalebic, N., Thomas, T., Argent, S. and Taylor, P. (2021). To what extent do children of parents/carers who are/have been imprisoned feel stigma? A systematic review. PROSPERO 2021 CRD42021261627 Available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42021261627](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021261627) (Accessed on 30 April 2022)

Thomas, T., Kalebic, N., Argent, S. and Taylor P, J. (2022) '*To what extent do children of parents who have been in prison feel stigma? A systematic review*'. Presented at the Royal College of Psychiatrists, Faculty of Forensic Psychiatry Annual Conference 2022

The fourth reference relates to a poster on a systematic review which I conceived and led on as part of the reviewing work for my thesis (chapter 2). The poster was presented at the RCPsych International Conference 2021:

Kent, J., Taylor, P., Argent, S., & Kalebic, N. (2021). Experiences of children who have been separated from a parent due to military deployment: a systematic review of reviews. *BJPsych Open*, 7(S1), S263-S263. doi:10.1192/bjo.2021.702

As above, this work stemmed from my literature reviewing work in chapter 2 of my PhD thesis. SA conceived the questions and developed the search strategy. SA prepared the protocol for the review including the inclusion and exclusion criteria. SA ran the search and prepared a data extraction table. NK and SA sifted 100 results to ensure reliability and SA sifted the remaining titles. Full texts were reviewed by SA with discussion with PJT and NK. Jennifer Kent was on placement as a medical student with the department and undertook data extraction, with SA also completing this for one review to ensure reliability. JK wrote up a first version of the project which was presented in the poster.

SA then updated the search again and identified further reviews. The text in chapter 2 relating to this literature reviewing work draws on the data extraction performed by JK and was written having worked with JK, NK and PJT on the poster for the conference. JK, SA and NK are currently working on an updated search strategy and a revised protocol, which JK has submitted to PROSPERO.

## ACKNOWLEDGEMENTS

My thanks go first to the participants who gave up their time to speak to me so openly and insightfully about their experiences. It was such a privilege to hear from you about your experiences and I thank each of you for your contribution.

I must thank the students who had collected data from the clinical records for the quantitative work in this thesis – Laura Riddleston, Jodie Warr, and Hannah Tippetts, and all the health care professionals who helped me to recruit to the qualitative study, especially the social workers at Caswell Clinic. Thank you too, to Jennifer Kent for her diligent hard work whilst on placement with the department.

Great thanks and gratitude go to both of my supervisors, Pamela Taylor, and Fran Rice, for their guidance, support and patience throughout my PhD studies. Thank you too to Natasha Kalebic for her constant support and encouragement.

Finally, to those who have supported me and believed in me since I first mentioned that maybe a move to Cardiff was a good idea. You weren't all here at the beginning of the journey and you haven't all been able to see that I made it to the end, but I wouldn't have got here without the support and belief of each of you.

First, there are several feline family members without whom the journey to thesis completion would have been much more fraught, and so thank you for your company, quiet presence, and affection – Fizz, Smudge, Reacher and Schubert.

To all my friends, but especially to Riley and Jenny for their quiet confidence that I would complete this. Thank you to Stuart for always being available when I needed to talk, and perhaps particularly for being there when I thought I didn't need to talk.

To Tim, my husband, thank you for thinking that moving to Cardiff was obviously the best way forwards (and for never looking back), for believing in me and supporting me. To Tom, for being the best brother I could have, and to Mamgu, for always being there and quietly believing in me. Finally, to James Alfred for showing me that there are bits of my heart that I never knew existed – I love you, son.



## **Chapter 1: Introduction**

### **1.1 Introduction**

This thesis will consider the experience of the offspring of parents who are, or who have been, detained in secure forensic psychiatric hospitals. Such hospitals are used primarily when a patient has a mental disorder requiring treatment in hospital but has also committed a serious offence. Because of the risk to others, these forensic hospitals have physical and procedural security in place, which separates them from ordinary community life and poses barriers to children and other family members visiting. The children and adult offspring of parents detained in such circumstances have not been considered in the research literature to date.

In this introductory chapter, I consider firstly why experience in childhood and adolescence matters, providing an overview of the literature on adverse childhood experiences (ACEs). I focus on the studies conducted in Welsh and English populations as these are the nations from which the research data will be drawn in the empirical work in this thesis. I then describe some of the features of the secure forensic psychiatric hospitals, in which these offspring's parents are detained, ahead of a brief description of the characteristics of these hospitals' inpatient populations. An overview of the limited literature available, which considers this patient population's experience of parenthood then follows, before I consider the little which we can discern about the offspring at present. I will then describe the aims of this thesis.

### **1.2 Children and young people and adverse childhood experiences**

Adverse Childhood Experiences (ACEs) are increasingly recognised both nationally and internationally as common experiences in the general population, which confer an increased risk of mental health problems, health harming behaviours, and antisocial behaviours (Anda et al., 2005). They have also been associated with poorer physical health in adulthood, but this link has not been as well evidenced (Felitti et al., 1998; Felitti and Anda, 2010; Merrick et al., 2019).

There are 10 original ACE categories (Felitti et al., 1998). Five of these involve the child being directly harmed by a primary caregiver, and include physical, sexual, and psychological abuse, as well as physical and psychological neglect. The remaining five categories involve the child's home environment. They include the child being exposed to inter-parental violence, the child's parents separating, and a close family member being affected by mental disorder, alcohol and/or other substance misuse, or detention in prison (Felitti et al., 1998).

The effect of ACEs has been shown to be cumulative in nature; therefore, experiencing more ACEs, as with nearly all risk exposures (Rutter, 1978), is associated with poorer long-term outcomes (Bellis et al., 2014). There are however, difficulties in accurately ascertaining the prevalence of ACEs in any population, with record surveys and prospective longitudinal studies often under reporting prevalence, whilst retrospective studies may introduce sampling and memory biases (Baldwin et al., 2019). No observational study alone can detect causality, and randomised controlled trials (RCTs), which can, would self-evidently be unethical in this context (e.g., Rutter, 2007). Nonetheless, there is a growing body of literature on this, including specific examination of Welsh and English populations.

The Welsh Adverse Childhood Experiences Study (Bellis et al., 2015) involved a cross-sectional survey of 2028 adult residents in Wales. Nearly half (47%) of those surveyed reported having experienced at least one ACE and 14% had experienced four or more. The study reports that it used a well-established survey tool to elicit participants' childhood experiences, which covered the 10 original ACEs. In this study (Bellis et al., 2015), the authors find that what they term 'verbal abuse' - which seems to be defined similarly, although more narrowly, than the original ACE of psychological abuse - and 'parental separation', were the most frequently reported ACEs, at 23% and 20% respectively. Living with an adult with mental illness was reported by 14% of respondents, whilst living with an adult who had been imprisoned was reported by 5% of respondents (Bellis et al., 2015). It is worth noting though that other research indicates that these reports of adverse childhood experiences may be an underestimate. For

example, a health records data study showed that 1 in 4 children under 16 years old had a mother with a diagnosis of depression or anxiety (Abel et al., 2019). The underreporting may be because of many factors, perhaps including that those retrospective reports require accurate recall of events, and even if recalled, the reporter needs to also have an understanding that the nature of their experience was due to, for example, parental mental disorder or intoxication (for example, Eyre et al., 2014).

An English household survey (Bellis et al., 2014) reported that a similar number of respondents (46%) had experienced at least one ACE, but only 8% (compared to 14% in the Welsh study) had experienced four or more. A similar percentage, 12% (versus 14%), had lived with an adult with mental illness growing up, and 4% (versus 5%) had had a household member detained in prison. Parental separation and 'verbal abuse' were again the most frequently reported ACEs experienced, reported by 23% and 17% respectively.

Since the initial ACE Study (Felitti et al., 1998), researchers have looked beyond the original ACEs to encompass other childhood difficulties, which they have thought would have comparable physiological impact on the developing brain. The Philadelphia Expanded ACE Study examined the prevalence of what they refer to as 'community ACEs' (Cronholm et al., 2015). These comprise witnessing violence, felt discrimination, adverse neighbourhood experience (neighbours appearing untrustworthy and a feeling of being unsafe in the local area), being bullied and having lived in foster care (Cronholm et al., 2015). Building on this, researchers have started to explore whether community interventions can ameliorate the negative impact of children and young people's adverse childhood experiences (Matlin et al., 2019).

A recent review (Asmussen et al., 2020) concluded that negative experiences beyond the original 10 ACE categories, including social, as well as household and individual experiences, do also predict poorer outcomes in adulthood. Specifically, they list low family income, low birth weight, childhood disability, being bullied as a teenager and social discrimination as also being noteworthy ACEs. One of the review's recommendations is that future studies should look beyond the 10 originally identified

ACEs and encompass a wider range of childhood adversities. This recommendation has been repeated in a prospective cohort study too (Houtepen et al., 2020).

Whatever the nature of the ACE(s), they impact on children's development in multiple ways, including the child's mental health but also social and functional outcomes, as well as indicators of biological functioning and physical health. ACEs are also important because the effects are long lasting with effects on mental health and functioning still being seen in middle age, (even when controlling/adjusting for earlier childhood/adolescent difficulties) (Selous et al., 2019).

The children of parents detained in secure settings will have experienced several ACEs by definition - they have a parent with a severe psychiatric disorder, possibly with comorbid alcohol and/or other substance related diagnoses, who has also committed a violent offence or otherwise been evidenced to present a serious risk to others. Given observations that adversities within the family, such as parental psychiatric disorder, tend to co-occur with other adversities, such as family discord (e.g., Rutter and Quinton, 1984), again add to concern that offspring of secure hospital patients may have experienced a wide range of adversities.

### **1.3 Introducing secure hospitals**

Secure forensic psychiatric hospitals in England and Wales are categorised as being of high, medium, or low security. There are only three high secure hospitals in England and Wales, and they are all situated in England, although serving both populations. These hospitals were once far more populous than they are today and comprised the entirety of secure psychiatric care until the latter half of the 20<sup>th</sup> Century. Today they collectively provide around 700 beds (Hare Duke et al., 2018) and include Broadmoor Hospital in Berkshire, which covers London and the South of England, Ashworth Hospital in Maghull, Liverpool, which covers West England and also accommodates Welsh men, and finally Rampton Hospital in Nottinghamshire, which covers the North of England and



additionally provides specialised high secure services for women and people with an intellectual disability from across England and Wales (Williams et al., 2020). It is easy to see that for families of Welsh men in Ashworth, or Welsh women, or Welsh men with an intellectual disability, in Rampton, particularly for families who are resident in South Wales, the practicalities of visiting in person would be considerable. Cardiff to Maghull, Liverpool, is a little over 200 miles in distance, and even with private transport, at least 3 and a half hours travelling time, and there are the financial implications of such a trip to consider too. There may also be, in the case of children, worries on the part of the parent(s) or carers, about taking a child to a high security hospital.

Medium secure services developed following concern that many people were being detained in conditions of high security when this was no longer proportionate to their ongoing risk. Their inception was in response to the Glancy (1974) and Butler (1975) reports and they were built in a planned manner and aimed to meet the needs of their local region; hence they were originally called *regional* secure units, only later being termed medium secure units. There are around 57 medium secure units in England (Völlm et al., 2018) providing approximately 3,500 beds (Hare Duke et al., 2018). These hospitals are therefore more accessible in terms of geographical proximity to the patient's home address, but the South Wales medium secure unit, Caswell, based in Bridgend, is still 80 miles (approximately 90 minutes by car) from Pembroke to the west and nearly 50 miles from places such as Chepstow and Usk in the east.

Low secure hospitals and services continue to be developed, primarily in response to local needs for inpatient psychiatric care, which is less restrictive than the physical and procedural security stipulations of a medium secure hospital. These low secure units have many similar physical security features to a medium secure unit, including a perimeter fence and a locked door (NHS England, 2018), and often tend to accommodate the chronically psychotically unwell patient during exacerbations of symptoms, which are likely to take longer to settle than the period to which a Psychiatric Intensive Care Unit (PICU) could usually commit. Low secure hospitals will also admit patients transferred from prison having committed less serious offences, and who are deemed to pose a 'significant', rather than 'serious' risk to others.

## 1.4 Secure Hospital Population

All three levels of security result in a restriction of the liberty of those patients who are admitted there, and adequate justification for the admission and ongoing care and treatment of each patient in such conditions is required. The rationale will include each patient's mental disorder, which must fall within the meaning of the Mental Health Act, 1983/2007 (UK Government, 2007), and which must be of a nature and/or degree warranting detention in hospital for medical treatment. Since the opening of medium secure hospitals, it has been consistently reported that most patients there have a diagnosis of paranoid schizophrenia (Earnshaw et al., 2018) and this applies to men and women (Tully et al., 2018). Other primary diagnoses reported include personality disorders, delusional disorder and affective disorders (Coid et al., 2007). Most secure hospital patients are men and only 12-15% of beds are occupied by women (Rutherford and Duggan, 2008).

For a patient to be detained in a secure hospital there must also be a proportionate level of risk to others, which may be accompanied by a risk to self. For an individual to be admitted to conditions of high security, their risk to the public is generally described as having to be 'grave and immediate' (Williams et al., 2020). There is a caveat in that the Ministry of Justice has discretion to direct a patient to be detained in conditions of high security in the absence of grave risk to others.

Patients detained in medium secure hospitals include people transferred directly from the prison estate – either having been sentenced or on remand (Kasmi, Duggan and Völlm, 2020) as well as patients who were initially detained in high security but whose risks are assessed as having reduced following treatment for their mental disorder and, often, other interventions too. Other pathways into medium secure settings include people moving up the levels of security when they can no longer be safely managed in less secure conditions, whether that be a low secure hospital, a PICU, locked rehabilitation, or very rarely an open unit or a community setting (although admissions directly from police stations are more common and this is considered to be a 'community setting') (Kasmi, Duggan and Völlm, 2020). To be detained in conditions of medium

security a patient should pose a 'serious danger to the public' (Rutherford and Duggan, 2008).

### **1.5 Studies of parenthood in a secure population**

Literature searches revealed just four publications which have considered parenting as part of the lives of secure hospital patients (Chao and Kuti, 2009; Gow et al., 2010; Parrott, MacInnes and Parrott, 2015; de Vogel et al., 2015) and three of these included consideration of the children to varying extents (Chao and Kuti 2009; Parrott, MacInnes and Parrott, 2015; de Vogel et al., 2015). Three of the four studies are UK based, 2 in England (both in the Southeast) (Chao and Kuti 2009; Parrott, MacInnes and Parrott, 2015), and 1 in Scotland (Gow et al., 2010) whilst the fourth study is based in the Netherlands (de Vogel et al., 2015). I will now discuss each of these in turn except for the Gow et al., study (2010) which simply mentions the 5-year-period prevalence of parenthood within the demographic information, and they found that a third of patients were parents.

Chao and Kuti (2009) who examined the point-prevalence across two medium secure hospitals in London, UK, found that 38% of women and 20% of men were parents. Children of father-patients were more likely to be living with their other parent than children of mother-patients; children of mother-patients were more likely to be involved in childcare proceedings. Less than a third of the parent-patients had contact with their child(ren) although children of mother-patients were more likely to maintain contact than children of father-patients (58% versus 32%). Only a third of mother-patients' and a fifth of father-patients' children were offered support in relation to the parent's 'health/offence issues'. When offered, this support was most usually provided by the hospital social worker. Reasons for an absence of contact and lack of support being offered by the unit staff included an absence of basic information around the child's whereabouts, or knowledge that the child had been adopted and contact was thus not possible. Other reasons cited included that a family member had been the victim of the offence, that the offence was against a child or that the child was frightened of the parent.

Parrott, MacInnes and Parrott, (2015) similarly found that 38% of women and 27% of men detained in one secure hospital were parents. Most parent-patients had one child aged under-18-years. Father-patients had a median of one child with a range of 1-5 children, whilst mother-patients had a median of 2 children with a range of 1-3 children. They found that two thirds of mothers and a quarter of fathers were in contact with their child(ren). Parrott, MacInnes and Parrott, (2015) conducted interviews with the parent-patients, which highlighted the importance to patients of their role as parents. However, the children's views were not sought in this study.

A Dutch study (de Vogel et al., 2015) found that 54% of women and 34% of men were parents, which is slightly higher than in other studies, but the reason for this is not easy to discern. Their multi-centre study also highlighted that most of the children were not living with their parent at the time of the parent's index offence. This was especially so in the case of the children of women inpatients. Children of father-patients were more likely to be living with the patient's partner than children of mother-patients, who were most usually (81%) living in foster homes, child protection settings or with relatives. About a third (32%) of the children of mother-patients were accommodated in an institution compared to less than a fifth (14%) of the children of father-patients. Literature to date therefore indicates that it is likely that at least a third of secure hospital patients are parents, with slightly higher rates of parenthood in women detained in such conditions than men.

## **1.6 Discerning something of the experience of the children**

In the absence of research involving the children of secure hospital patients beyond that described above, an alternative approach to try and understand their situation is to examine research which involves any one of the various facets of the offspring's situation and extrapolate the likely importance of researching the children's actual situation, from this.

As a starting point to this approach, given that patients in secure hospitals must be detained under the Mental Health Act 1983/2007 (UK Government, 2007), we know that the parent must have a mental disorder. When a parent has a severe psychiatric disorder, the offspring may be affected in one or more ways:

1. Genetically (e.g., Rasic et al., 2014).
2. Through maternal environment *in utero*, for example by exposure to maternal stress hormones, especially cortisol (Aktar et al., 2019) and/or any prescribed or non-prescribed substances (Creeley and Denton, 2019).
3. During childhood
  - i) directly by the parent's symptoms including hallucinations, delusions and apathy or anhedonia (e.g., Thomas and Kalucy, 2003).
  - ii) by parental disorder-related impairments in interpersonal interaction, possibly affecting the child's attachment style (Murray 1992).
  - iii) through the way the child is enabled to understand the parental mental disorder, for example, believing that they are responsible in some way for the parent's symptoms (Stallard et al., 2004).
4. By the wider environment around the child-parent dyad, including
  - i) the presence or absence of the other parent and the nature and quality of that relationship (Rutter, 1979; Collishaw et al., 2016).
  - ii) the extent of illness-related interparental discord, financial worries, social isolation and stigma (Reupert and Maybery, 2007).

There are several systematic reviews which have examined various offspring outcomes when a parent has a serious mental disorder. Such reviews often capture offspring inherited and environmental liability to psychiatric difficulties including diagnosed psychiatric disorder (Mendes et al., 2011; Rasic et al., 2014; Lau et al., 2017), and/or increased internalising or externalising behaviours (Connell and Goodman, 2002). Internalising and externalising behaviours are often identified through application of the Child Behaviour Checklist (CBCL). The CBCL defines internalising problems as depression, anxiety, and withdrawal, and externalising problems as rule breaking and aggressive behaviour (Achenbach and Rescorla, 2001). Less frequently, and predominantly when the

parental diagnosis is one of personality disorder, other child measures are examined, such as changes in household composition and/or school, child physical health symptoms and child-parent role-reversal (Petfield et al., 2015; Eyden et al., 2016). These quantitative systematic reviews are discussed in more detail in the second chapter of this thesis, which includes a review of systematic reviews of quantitative research concerning the experience and outcomes of offspring who have a parent who experiences mental disorder.

There is also a body of qualitative research literature concerning the experience of children who have a parent who has a psychiatric disorder. A systematic review of qualitative studies (Yamamoto and Keogh, 2018) used thematic analysis to draw out four themes across their included literature, which involved 91 participants from 8 studies. The first theme was children's understanding of parental psychiatric disorder. Regarding this theme, a clear message came through about the difficulties children had in gaining enough, helpful information, regarding the parent's psychiatric disorder. The second theme was the child's relationship with their unwell parent, which included role-reversal and wider family disruption due to the parental psychiatric disorder. Stigma came through too, in both the children's own fears of being stigmatised, and the parent not wanting the child to speak about their illness. The third theme was children's coping strategies, which varied with age. Strategies included seeking refuge in pets and cuddly toys as younger children, but in friends, activities and taking time out as older children. Some children sought refuge in alcohol and other substances too. As well as taking a break from the parent in these ways, children also coped by trying to help the parent, whether through affection or practical assistance. The fourth theme was social connectedness, which also indicated the role of stigma in these children's lives, with children sharing only with a small and carefully chosen group. Children also reflected on an absence of support from mental health professionals. There was one mention of children gaining strengths through their experience, with them reporting increased maturity (Yamamoto and Keogh, 2018).

Specific aspects of offspring experience in the context of parental mental disorder have also been considered in the research literature, including the experience of children and young people (age range not specified) who take on the role of carer for a parent with a mental disorder (Cooklin, 2010). Cooklin (2010) estimated that between 55 and 60 thousand children may be caring for a parent with a mental illness at any one time in England and Wales. This paper also highlighted research by Dunn (1993), which indicated that whilst superficially children who are carers may seem to be coping, retrospective reports by such children in adulthood revealed narratives of abuse, neglect and isolation.

Another specific aspect of potential offspring experience in the context of parental mental disorder, is the experience of children who visit a parent in an acute psychiatric hospital, which was considered in one paper (O'Brien et al., 2011a). O'Brien et al., (2011a) interviewed five children aged 8 to 15 years old. Children were quoted as finding the unit 'daunting' and being afraid of people doing 'odd things'. The paper also mentioned that children were not sure if they would be safe. Children reported finding it difficult being 'stuck in a room with nothing to do'. They also found it difficult that staff did not talk to them, saying 'I wasn't sure what to ask.... but I did want to talk to them'. Children expressed concern about their parent and reflected on the difficulty of saying goodbye at the end of the visit and on their worries about having said the 'wrong thing' and thus having exacerbated their parent's illness. Again, staff support with this was desired. Children also expressed a wish to be involved, with one expressing that 'you shouldn't be left in the dark because you're a kid and maybe they don't give us credit.... You can handle it. It is much more scary not knowing'. Other expressions of desire for information included 'we need more understanding about what's happening' and that staff 'should be there to explain what is happening and why [the parent] is in there'.

Another key facet of offspring experience if a parent is detained in a secure setting is that their parent must pose a risk to others substantial enough to warrant restricting their liberty. A parallel of this, with or without mental disorder, is having a parent in prison. Just over half (53.3%) of one cohort study of medium secure hospital admissions had been transferred directly from prison (Doyle et al., 2014). Having a parent in prison is an

ACE in itself and affected children are at increased risk of developing anti-social behaviours (Murray, Farrington and Sekol, 2012). Skinner-Osei and Levenson, (2018) discuss the shame and stigma these children experience, and the complexities of grieving for a parent who is alive but physically removed.

Not only may the medium secure hospital parent patient have been in prison previously, but the offending behaviour leading to their detention is likely to have comprised at least one seriously violent offence. Lelliott, Audini and Duffett, (2001) found that about a third of an inner London medium secure hospital sample had committed at least one act of severe violence, including crimes in which the victim had died, or in which their life was seriously endangered, and crimes which comprised rape or attempted rape. This has relevance for the child beyond the parent's possible detention in prison prior to being in a secure hospital, as the child, a child's sibling, or the child's other parent, may have been the victim of the index, or any prior, offence. Furthermore, the child, if not the victim, may have been a witness. It may also be that the parent-patient had committed previous violence, perhaps in the home, possibly against the child or other family member, with or without resultant criminal conviction.

In thinking about the parent patient's history of risk to others, there is literature on child outcomes when exposed to inter-parental violence and this is also an ACE. Research has tended to focus on child externalising and internalising signs and symptoms, although there has been some consideration of trauma symptoms too, such as flashbacks of witnessing such violence, hyper-arousal or emotional withdrawal (Evans, Davies and DiLillo, 2008).

In addition to the ACEs already outlined, which offspring would have experienced, there is a further crucial facet to offspring experience when the parent is detained in a secure hospital - the fact that the parent and child are physically separated. This significance of such separation is aptly described in attachment theory (Bowlby, 1988). This details how caregiving disruption in early life can adversely affect a person's relationship with him/herself and with others throughout their lifespan. Brown et al., (1977) also considered the relationship between loss of a parent, whilst the child was aged under 17



years, through either the death of the parent, or separation from them for at least a year due to other cause, such as hospital admission, and subsequent psychiatric illness.

Women who had lost a mother before the age of 11 years were more likely to have had a depressive episode in the year prior to the researchers' interview with them than women who had not suffered such loss (Brown et al., 1977). Rutter, (1972) however showed that this association was linked to inadequate care of the child following the mother's death, rather than the death itself, which highlights the need to understand in more detail the experience of the child and the nuances of each situation, not just the presence or absence of specific adverse childhood events.

### **1.7 Summary**

It is evident that the offspring of parents detained in secure psychiatric settings inherently face a number of difficulties, which when they occur in childhood would be classed as adverse childhood experiences (ACEs). These include, as a minimum for these children, both parental psychiatric disorder and parental offending behaviour, as well as possible parental alcohol and/or substance misuse. A further key problem for these offspring is the mandated physical separation of the parent and child, which occurs in a context which may make the separation itself more difficult for the child to cope with. In the absence of any research into the actual experiences of the offspring – as children or as adults - it is difficult to know, however, the extent of any problems, or what, if any, support and/or interventions may be required. This needs remedying and we also need to know what features might mitigate the anticipated risks to the child's development and/or whether these offspring develop any strengths because of their experience.

### **1.8 Aims**

In this thesis, therefore, I aimed to remedy this gap in the research literature regarding the offspring of people detained in a secure forensic psychiatric hospital with a mixed methods study.

My first aim, following a mapping exercise and several scoping searches, which I have described in chapter 2, was to complete a review of systematic reviews on quantifiable offspring outcomes, including problems, needs and strengths, associated with their experience of major parental psychiatric disorder(s), focusing on schizophrenia, affective illnesses, and personality disorder(s). I then placed this in the context of evidence from the literature pertaining to the other two key facets of offspring experience – parental risk to others and child-parent separation.

My second aim was to use routinely collected clinical data to:

- i) find the prevalence of parenthood in a 9-year admissions cohort from one regional secure hospital unit
- ii) describe parent-patient attributes, including the parent's psychiatric disorder and offending behaviour before admission
- iii) examine the nature and extent of any change in contact between child and parent from the year before, to the year after, parental hospitalisation.

My third aim was to interview adult-aged offspring who have had a parent detained in a secure hospital. I used grounded theory methods to find a theory and model of their experience. The focus of this work was on adult aged offspring for several reasons. First, this allowed the decision about participation to rest entirely with the offspring; complex issues around parent or guardian consent would have arisen with offspring below the age of 18 years. Secondly, given the lack of information on these offspring and the concerns regarding the extent of adversities experienced by them, it was important to have some understanding of this from adult offspring before approaching an arguably more vulnerable group of dependent children. Thirdly, I considered that with these legal and informational complexities, the ethics of an initial approach to young children would be questionable and, indeed, questioned by any independent research ethics committee.

## **Chapter 2: Scoping literature searches to explore the extent of research regarding each facet of the offspring experience in the context of a parent's secure hospital admission and preliminary comment on the available findings**

This chapter is an amended version of a published paper, which is referenced below:

Argent, S.E., Kalebic, N., Rice, F. and Taylor, P. (2020). Offspring outcomes when a parent experiences one or more major psychiatric disorder(s): a clinical review. *Evidence Based Mental Health*, 23(3), pp.113–121.

My contribution to this publication is outlined in the preface.

### **2.1 Chapter Overview**

As summarised at the end of Chapter 1, the offspring of secure hospital patients face a number of adverse experiences, including severe parental psychiatric disorder, the serious risk the parent poses to others and the enforced child-parent separation. In this chapter, I have described how I conducted a mapping exercise to inform my literature reviewing. The main piece of work to emerge from this was my review of systematic reviews on offspring outcomes in the context of major parental psychiatric disorder. All offspring of secure hospital patients have at least one parent with major psychiatric disorder(s) so this is fundamental. This chapter also expands that work by outlining the wider context identified in the mapping exercise, and provides overviews of literature from scoping searches, which relate to the other key facets of offspring experience – parental risk to others and parent-child separation. In the review of systematic reviews, I sought to describe the evidence on quantifiable offspring outcomes, including problems, needs and strengths, associated with their experience of major parental psychiatric disorder(s), focusing on schizophrenia, affective illnesses and personality disorder(s). I identified seven high-quality reviews, which incorporated 291 unique papers, published 1974–2017. The weight of evidence suggested increased risk of poor offspring outcomes, including psychiatric disorder and/or behavioural, emotional, cognitive or social

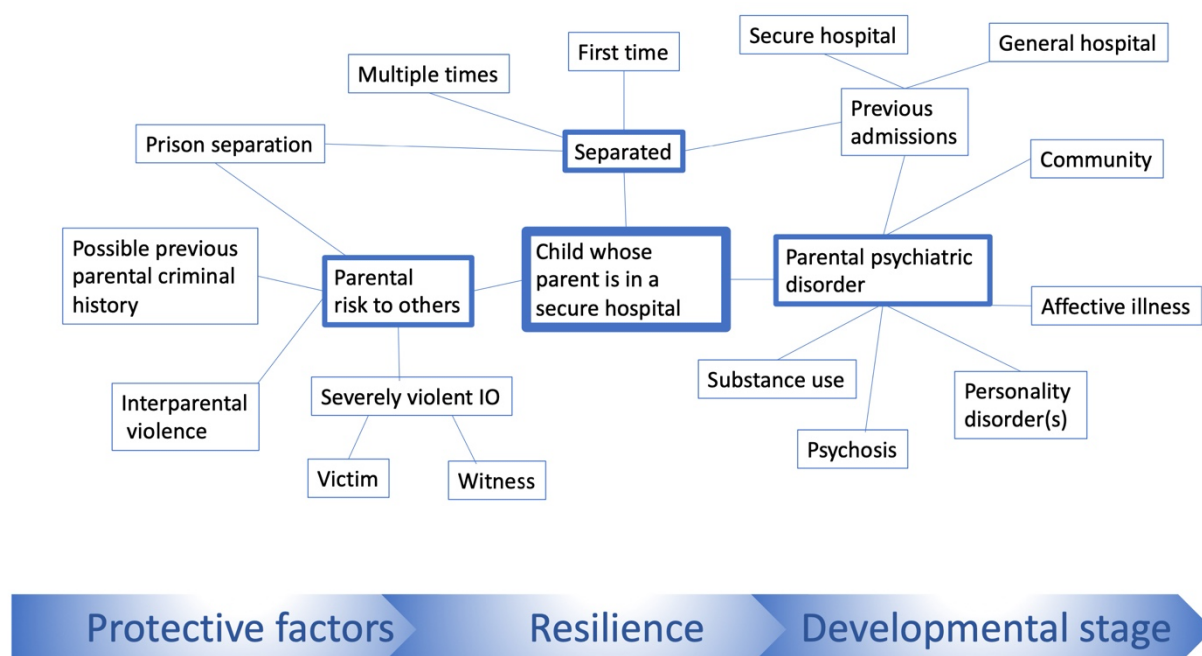
difficulties. No review explored child strengths and relatively few considered resilience promoting factors although this has been explored in primary research (for example, Collishaw et al., 2016). I describe the findings of the review in this chapter and relate them to the broader context of likely offspring experience before introducing a developmental psychopathology perspective to thinking about offspring experience.

## **2.2 Introduction to the chapter**

As outlined in Chapter 1, offspring of secure psychiatric hospital patients experience three key facets to their experience, which comprise the parental major psychiatric disorder, the parent's serious risk to others, and the mandated physical separation of the offspring from the parent during the parent's secure hospital admission. In order to think further about these facets of the offspring experience, and how these might be captured in the existing research literature, a mapping exercise was undertaken.

The mapping exercise is represented diagrammatically in figure 2.1 and I will describe the thinking involved in creating this before exploring each of the three main aspects of offspring experience, in turn, later in this chapter. The starting point on figure 2.1 is the central box shown – which indicates my population of interest - the child(ren) of a parent detained in a secure hospital. The first facet is that it is known that the parent must have a mental disorder in order for them to be detained in hospital under the Mental Health Act 1983/2007 (UK Government, 2007). The mental disorder may involve psychosis, personality disorder, an affective illness, or any combination of these, and any of these presentations may be complicated by substance or alcohol use although this alone would not be sufficient for detention. The psychiatric disorder may be longstanding, and the parent may have had previous admissions to hospital, either in an open unit or in a secure hospital. Alternatively, the psychiatric disorder may have been treated solely in the community. Any previous admission would also constitute a previous parent-child separation.

**Figure 2.1. Diagram showing a mapping exercise which was undertaken to think through what the experience of children who have a parent in a secure hospital may include. IO = index offence.**



The second key facet of the child's experience is that their parent must pose a serious risk to others. This must be present to warrant the parent's detention in secure conditions. Whilst the index offence or incident leading to the current parental secure hospital admission may be the first of its kind, it may also be part of a longer standing pattern of behaviour. Previous parental behaviour presenting risk to others may have resulted in periods of imprisonment, which would constitute another parent-child separation. The other concern, when thinking about parental risk to others, is that this may have manifested itself in the home, and even if there had only been the one index offence, this may have been witnessed by the child, or the child may even have been the victim.

Separation from the parent is the third key facet of the offspring experience, which will have been experienced by the child whilst the parent is in a secure hospital. The current parental admission may be the first child-parent separation. However, separation of the

child from the parent may be longstanding, predating the current secure hospital admission, or may have occurred on more than one occasion previously.

The boxes at the bottom of figure 2.1 developed from recognition that any of the above events occur in a wider context, which includes other factors external to the child, and which may potentially be protective, such as a consistently present and effective other parent or carer. The child may also have inherent resilience through, for example, secure attachment or good self-esteem. Resilience may also be an outcome relating to the offspring experience of the parent's secure hospital admission, or other related, or unrelated, experiences. All these things happen in the context of the developmental stage of the child. The diagram is not intended to be exhaustive in terms of the risk or protective factors incorporated but was a starting point to think about the offspring experience. I will now describe in more detail each of the three main facets of the mapping exercise.

The first element to be considered is that of the offspring experiences, outcomes and related processes in the context of parental major psychiatric disorder. Given that psychiatric disorder is familial and heritable, the child is likely to inherit genetic vulnerability for psychopathology and to experience an environment influenced by the parent's psychiatric disorder. Nonetheless, a genetic predisposition to psychiatric illness is probabilistic rather than deterministic (Rutter and Sroufe, 2000). My research question for my review of systematic reviews was 'what quantifiable offspring outcomes, including problems, needs and/or strengths, are associated with their experience of major parental psychiatric disorder(s)?' This work culminated in a published review of systematic reviews. Later in this chapter I will describe and justify the reasons to focus on undertaking a review of systematic reviews and describe the review itself. I will also briefly consider the wider context in which that review sits, focusing on the risk the parent poses to others and the mandated separation of the parent and child.

In considering the second element of offspring experience, the serious risk which the parent must pose to others, I will explore this from two angles. One angle is in terms of the parent's potential risk to others within the family unit, as captured in figure 2.1 in the box 'interparental violence'. I focus on interparental violence in the literature searches and incorporate the risk to the offspring through their direct, or indirect, involvement. Such involvement could be through exposure to the inter-parental violence, or through their response to it, such as self-blame. My research question here was 'what evidence is there in the research literature regarding offspring outcomes when exposed to interparental violence?' Although I have used the term interparental for ease of reading, literature on violence between the child's parent and a partner other than the child's other parent was included. There was a myriad of ways in which I could have explored the literature on this crucial facet of offspring experience of parental significant risk to others. There were, with all facets, inevitable limitations to any one direction of exploration: this was one of the challenges inherent in exploring literature which sought to capture a facet of offspring experience in the absence of literature on the actual experience of the offspring of secure hospital patients.

To try and ameliorate some of the limitations in exploring only the main facets of the offspring experience, and to add breadth to the exploration of the literature regarding offspring outcomes in the context of parental risk to others, I also examine the issue of parental incarceration. This was chosen given that many secure hospital patients have previously received custodial sentences (Doyle et al., 2014). I ask the question 'what evidence is there in the research literature regarding offspring outcomes when a parent has been incarcerated?' This area also relates to the third element of offspring experience, which is parent-child separation, and it is of course possible that the parent was imprisoned for an offence which less directly poses a risk to the child, however I will discuss it in the parental risk category with this caveat in place.

The third element considered is the hospital admission mandated parent-child separation. Parent-child separation may occur in various situations. It was considered in the context of parental divorce by Amato and Keith, (1991). They describe three theoretical mechanisms by which parental divorce may lead to decreased wellbeing in children, all of which could also apply to children separated from a parent due to parental secure hospital admission. These three mechanisms include 1) the loss of the parent as a role model, for emotional and practical support 2) socioeconomic impacts of the loss of the parent and 3) inter-parental conflict. Nonetheless, there is also evidence that in some circumstances the removal of a parent can be beneficial for children's wellbeing, for example, as in the case of fathers with high levels of anti-social behaviour (Jaffee et al., 2003), and this too may be applicable to offspring with a parent detained in a secure hospital.

In thinking about different ways in which the research literature may capture parent-child separation in situations which may be comparable to the experience of secure hospital patients' children I considered several angles. These different angles include parent-child separation due to parental employment, parent-child separation due to evacuation of either parent or child, parent-child separation due to the death of a parent, and parent-child separation due to parental military deployment. Each of these areas are considered briefly in turn.

Once the three different aspects of offspring experience have been examined, I then summarise the similarities and differences in the associations with offspring outcomes for each element and finish with suggestions for future research. Ultimately, the facet of being an offspring of a parent who has a major psychiatric disorder was the aspect of offspring experience which I explored in the literature with the most systematic and rigorous methods. All facets however, were explored in the literature using systematic methods, such as using the same search terms across the same range of electronic databases. However, the facet of offspring experience in the context of major parental psychiatric disorder was explored with additional systematic procedures to ensure



robustness, including quality assessment of potential systematic reviews to be included in the synthesis, and two researchers conducted the data extraction for all included reviews. Whilst I made every effort to conduct exploration of each facet of offspring experience in a systematic manner, resources did not allow each facet to be explored with the same degree of rigour. The facet of offspring experience of having a parent with a major psychiatric disorder was prioritised for the most rigorous, systematic literature reviewing as it was the facet which could be tailored most readily to reflect the population of secure psychiatric hospital patients.

## **2.3 Parental psychiatric disorder**

### ***2.3.1 Introduction***

Although the facet of experience of having a parent with a major psychiatric disorder was ultimately that which was reviewed systematically and in depth, even discerning the best approach to scrutinising the literature on this topic of parental psychiatric disorder necessitated a number of scoping searches. These scoping searches were required as there were several approaches one could take to the topic. The first avenue which was explored in the literature, was that of offspring experience and outcomes when a parent is, or has been, admitted to a psychiatric hospital. A parent admitted to an open unit would have at least a suspected mental disorder and the parent and child would also be separated by the parent's admission. This population was therefore thought to closely resemble the current population of interest (i.e., the children of parents who have had a secure psychiatric hospital admission).

However, it proved that this population was under-researched. A scoping search in 2017 employed the search terms '(parent\* or mother\* or father\* or maternal\* or paternal\*) AND (mental\* or psychiatr\*) AND (hospital\* or inpatient\* or admission\* or detention\* or incarceration\* or facility) AND (child\* or son\* or daughter\* or offspring)'. The search

terms intended to be inclusive rather than exclusive and sought an international perspective so did not require search terms relating to 'formal' or 'informal' detention/admission, although this general distinction was sought to be captured in the reference to either 'admission\*' or 'detention\*'. The search revealed just one relevant paper which considered offspring experience of parental psychiatric hospitalisation, by O'Brien (2011a), as described in Chapter 1. A few other papers on the topic were identified but these were published in the 1950s and 1960s and could not be relied upon to reflect the experience of offspring of patients in the modern secure estate. Given the paucity of information available, scrutiny of other related areas of the research literature was considered appropriate.

Further scoping searches of the research literature therefore sought to establish the volume of literature which reported on the experience and outcomes of children whose parent had a severe and enduring psychiatric disorder, without specifying a history of inpatient treatment. A number of scoping searches, performed in 2017 and updated in 2018, indicated that the literature was extensive. Effort was made to try and specify the nature of the parental disorder in terms of the severity and duration but it was noted that studies looking at offspring experience or outcomes did not usually specify a minimum duration of parental illness, nor did they specify severity of the parental disorder (e.g. as necessitating prior hospital admission(s)).

There were however other refinements to the literature to be included, which could make the findings more applicable to the population of interest in this thesis. For example, publications focusing on the perinatal period, which was itself an extensively researched area, were excluded, as there is currently no provision for pregnant women in secure hospitals in the United Kingdom and no secure mother and baby psychiatric facilities. The area of research on the perinatal period was also so extensive as it would have risked overshadowing the findings regarding older offspring. Research was also excluded which focused on parental sub-diagnostic threshold difficulties or exclusively substance related diagnoses, as such clinical scenarios would not warrant detention in a

secure hospital. Searches were tailored to focus on the more prevalent diagnoses among patients in a secure hospital - psychosis, affective illnesses and personality disorders. Even after these refinements in search terms and more detailed exclusion and inclusion criteria, it remained evident that the literature was extensive in this area, and that several systematic reviews had already been undertaken. Subsequent reviewing of the literature in this area was therefore focused on reviewing already published peer reviewed systematic reviews and meta-analyses.

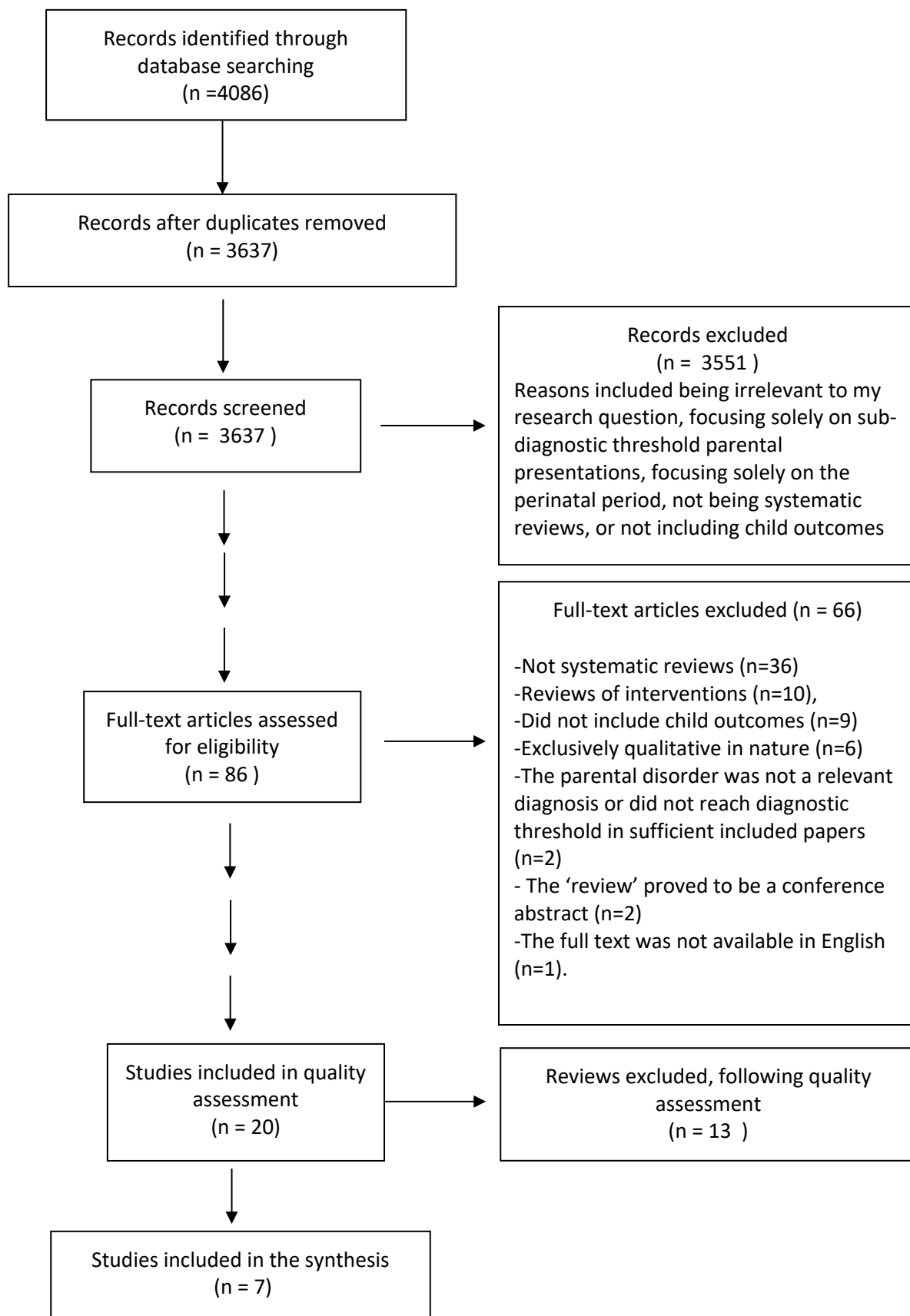
The review posed the question 'what quantifiable offspring outcomes, including problems, needs and/or strengths, are associated with their experience of major parental psychiatric disorder(s)?'

### **2.3.2 Methods**

Seven web-based search engines were searched (OVID Medline®, EMBASE, PsycINFO, AMED, Joanna Briggs Institute EPB Database, Scopus and Web of Science) from inception to February 2018. Key words were used as search terms to capture major psychiatric disorder(s), focusing on schizophrenia, severe affective illnesses and personality disorders, and to capture the parent-child relationship. Search terms for offspring outcomes were not applied to avoid our expectations limiting the search. Major subject heading (MeSH) terms were used where available. The key words used as search terms across the seven databases were (father\* or mother\* or parent\* or maternal\* or paternal\*) AND (mental\* disorder\* or mental\* illness\* or psychosis or psychotic\* or schizo\* or personality disorder\* or borderline personality or emotional\* unstable or emotional\* instab\* or complex post-trauma\* or psychiatr\* disorder\* or psychiatr\* illness\* or severe depress\* or bipolar affective or manic or mania or affective psycho\*).

Searches identified 3,637 unique records. The first 100 titles and, where necessary, abstracts, were rated independently by two researchers (SA, NK) against the inclusion/exclusion criteria. Inclusion criteria required papers to be systematic reviews of studies of quantifiable outcome measures, concerning sons/daughters of a parent with a major psychiatric disorder. Exclusion criteria eliminated reviews with unreported/non-replicable methods, solely sub-diagnostic threshold parental problems or reviews without quantitative child measures (for full criteria see Appendix A). Inter-rater reliability was 99%. Discrepancies were resolved through discussion. The remaining title and abstract screening was completed by one researcher (SA), leaving 86 papers. Full text examination by two researchers (SA, NK), left twenty reviews (figure 2.2).

**Figure 2.2. The search and selection process undertaken in identifying systematic reviews for inclusion in the synthesis.**



Quality assessment of these 20 reviews was undertaken by one researcher (SA) according to criteria across five areas which Maniglio (2009) describes as being consistent with the Centre for Reviews and Dissemination guidelines (2009). Maniglio (2009) also explained that these five areas need to be described in sufficient detail to enable replication. I will now detail the five areas. The first area is with regards to the review authors' evidence identification. In relation to this I examined whether the review authors stated that they had searched two or more electronic databases, whether any databases searched were named, whether the time frame in which studies were searched was stated, whether search keywords and/or MESH terms were stated, and whether authors documented that they had used one or more supplemental search method(s) such as reference searching or contacting experts.

The second area is with regards to review authors' study selection. For this, I examined whether the authors had searched for unpublished material, whether their inclusion and exclusion criteria were available, whether they had stated how many researchers had screened results for inclusion/exclusion, and whether there was a PRISMA diagram or equivalent information available. The third area is regarding review authors' data extraction. For this, I examined whether the data extraction procedure was reported, whether the authors had stated how many researchers had completed data extraction procedures, whether study characteristics such as participants, interventions and outcomes were reported, and whether the ranges of characteristics included in the studies were reported, such as participant age and gender. The fourth area was the presence or absence of any formal quality assessment of the studies by the review authors, and if present, indicators of thoroughness, and replicability of this. For this, I examined whether the studies in each review were formally quality assessed, and if so, whether the criteria were described, and whether the number of researchers who completed this was stated. If reviews were not formally quality assessed, I examined whether the inclusion/exclusion criteria were sufficiently detailed to have in part at least have ensured the calibre of included studies. The final area of quality assessment was with regards to the review authors' data synthesis and analysis. I examined whether the quality of the studies was given weight in the forming of conclusions, whether the methods used to form the conclusions were described, whether the synthesis considered

the strength and/or consistency of evidence across the studies, whether there was a statement regarding conflict of interest, whether the method used to synthesise the studies was appropriate and whether there was any evidence that an alternative method would have been better. If the method of synthesis employed was meta-synthesis, then I examined whether the approach was rigorous and transparent. If the method of synthesis employed was meta-analysis, then I examined whether the effect size(s) and odds ratio(s) were reported, whether heterogeneity was explored, whether any subgroup analyses were explored, if investigation of publication bias was described and whether confidence intervals and levels of statistical significance were described.

In performing the quality assessment of the reviews, I examined the full text and any supplementary material available against the criteria described in detail above. Each criterion was either adequately met, meaning that there were more respects in which the criterion was addressed than not, which resulted in a score of '1', not adequately met meaning that the criterion was either not addressed at all, or else met fewer aspects of the criterion than were left unmet, which resulted in a score of '0', or where the review was found to meet the criteria in as many respects as it did not meet the criteria, it was scored '0.5'.

Reviews which were rated 'good' (meeting all criteria and scoring 5) and 'fair' (scoring 4.5 or 4.0) were included. Reviews scoring 3.5 would have been discussed with PJT and NK but in the event no review scored 3.5 and those scoring less than 3.5 were excluded. Seven reviews were retained, see table 2.1. References from included reviews were scrutinised for further reviews, but none met our criteria.

Included reviews were first checked by SA to assess the degree of overlap in the included papers. Reviews were then examined by two researchers (SA, NK) who extracted data from all seven reviews. The data extracted included the review questions and their methods as described in tables 2.2 and 2.3. Information was extracted regarding the reviewer's question(s) and/or the aims, the databases searched and the time frame of the search, as well as the number of studies included in the review results, those studies' design(s), and from where the researchers had recruited their participants, for example

community clinics or inpatient populations – so the sample origins, with additional note of the country of origin of each study where detailed (see table 2.2). Further detailed information was also extracted from the reviews, including the gender of the parent(s) and offspring included, the offspring age, the parental diagnosis and the offspring outcomes examined, together with the data source for the offspring outcomes to capture whether the information came from the offspring directly, through a standardised interview for example, or if offspring outcomes were measured by parent or teacher report. An *a priori* decision was made to synthesise the findings into a clinical review. Synthesis involved scrutinising the extracted data to identify common offspring outcomes explored in the reviews and examining the weight of evidence in relation to these. This involved consideration of the number of studies across the reviews which provided evidence for, against, or which were inconclusive regarding any identified offspring outcome (for example, offspring internalising problems). Information regarding the comparison groups in any included studies was also extracted (for example, offspring of a mentally well parent of the same gender as the unwell parent) and considered in this context along with the parental gender and parental diagnosed psychiatric disorder (for example, schizophrenia). Data were also extracted regarding the individual studies included in the reviews including the study's sample size and age of offspring as well as the study design and any quality assessment of the study as performed by the reviewer(s).



**Table 2.1 Quality assessment of the reviews for the review of systematic reviews on parental psychiatric disorder**

<b>Review author and year of publication</b>	<b>Score for evidence identification</b>	<b>Score for study selection</b>	<b>Score for data extraction</b>	<b>Score for quality assessment</b>	<b>Score for data synthesis and analysis</b>	<b>Total score for review</b>
Beardslee et al 1983	0	0	0.5	0	0.5	1.0
Connell and Goodman 2002	1	1	1	0	1	4
DelBello and Geller 2001	1	0	0	0	0	1
Downey and Coyne 1990	0	0	0.5	0	0	0.5
Eyden et al 2016	1	1	1	1	1	5.0
Frias et al 2015	1	0	0.5	0	0.5	2.0
Goodday et al 2017	1	1	1	1	1	5.0
Gunlicks and Weissman 2008	1	0	0.5	0	1	2.5
Hameed and Lewis 2016	0	0.5	1	0	1	2.5
Jones and Bentall 2008	1	0	0.5	0	0	1.5

<b>Review author and year of publication</b>	<b>Score for evidence identification</b>	<b>Score for study selection</b>	<b>Score for data extraction</b>	<b>Score for quality assessment</b>	<b>Score for data synthesis and analysis</b>	<b>Total score for review</b>
Klimes-Dougan et al 2017	1	0	0.5	0	1	2.5
Lapalme, Hodgins and LaRoche 1997	0	0	0.5	0	1	1.5
Lau et al 2017	1	1	1	1	1	5.0
Leijdesdorff et al 2017	1	0	0	0	0	1.0
Mendes et al 2011	1	1	1	1	1	5.0
Narayan et al 2013	1	0.5	0.5	0	0.5	2.5
Petfield et al 2015	1	1	1	1	1	5.0
Rasic et al 2014	1	1	1	0	1	4.0
van Santvoort et al 2015	1	0.5	1	0	0.5	3.0
Webb et al 2005	1	0	0	0	1	2.0

**Table 2.2: Offspring outcomes when a parent experiences major psychiatric disorder - research questions, review sources, design patterns of included studies and their country of origin**

<b>Authors Publication date</b>	<b>Main research question(s)/aim(s)</b>	<b>Databases and final search date Other sources (Search terms in English only unless stated)</b>	<b>Number of studies Study designs Sample origins</b>	<b>Countries of origin of the studies included in the review</b>
Rasic et al 2014	What is the risk of mental disorder(s) in offspring of parents with severe mental illness (schizophrenia, bipolar disorder or major depressive disorder)?  Does risk extend beyond the disorder present in the parent?	MEDLINE/PubMed, EMBASE, and PsycINFO to end 2012  Reference lists were also searched	Total: 33 An unspecified mix of cross sectional and longitudinal studies  21 (64%) studies recruited unwell parents through clinics/hospital admissions +/- other methods	No geographical restrictions – studies were from the USA (11, 33%), 3 from Canada, 2 each from UK, Australia, Romania, Israel, and 1 each from Turkey, India, Spain, Holland, Palau, Switzerland, Finland, Sweden, Brazil, Denmark, Japan.
Goodday et al 2017	To test for associations between exposure to parental psychopathology in childhood and subsequent suicide-related behaviours in the offspring. To determine if any such associations differ by the type(s) and timing of parental psychopathology, gender of the parent and of the child, type of child psychiatric symptoms and family functioning	MEDLINE, CINAHL, EMBASE, PsycINFO, and Web of Science to March 2017  Grey literature - including dissertations/ theses, Child Welfare Information Gateway, Google Scholar  Reference lists were also searched	Total: 54  19 cross sectional, 24 longitudinal, 11 case-control studies  No further details given	No geographical restrictions - included USA (n=26, 48%), Denmark (n=5), Sweden (n=4), UK (n=3), New Zealand (n=2), 'Africa' (n=2), and 1 each from Belgium, Finland, Germany, Netherlands, Norway, Poland, Brazil, Korea, Puerto-Rico, South Korea, Taiwan, Canada

<b>Authors Publication date</b>	<b>Main research question(s)/aim(s)</b>	<b>Databases and final search date Other sources (Search terms in English only unless stated)</b>	<b>Number of studies Study designs Sample origins</b>	<b>Countries of origin of the studies included in the review</b>
Connell and Goodman 2002	To examine the relative strength of the association between psychopathology in mothers versus fathers and internalizing or externalizing disorders in their children	PsycINFO and ERIC – 1888 to 2001  Authors were contacted Notices were posted on Internet-based discussion lists for psychologists  Reference lists were also searched	Total: 134 separate samples reported. However, on manually counting the studies listed in Connell and Goodman’s appendix 4 I could only identify 127 separate studies.  28 studies used parent clinical samples, 39 used child clinical samples, and 67 used community samples.	Not stated
Mendes et al 2011	To test the association between maternal depression and depression in school-age children To test for moderating effects of environmental and social covariates	Medline, Lilacs, Scielo, Index Psi and PsycInfo 2004 to 2010  Portuguese, Spanish & English search terms used	Total: 30 16 longitudinal (9 community, 4 clinical and 3 mixed samples) 14 cross sectional (6 community, 6 clinical and 2 mixed samples)	24 (80%) from the USA; one each from Brazil, Chile, England, Germany, Hungary, and Malaysia
Lau et al 2017	To examine the relative risk of a range of affective and non-affective psychopathologies among offspring of at least one parent with bipolar disorder compared to offspring with no parental major psychiatric history	Medline, PsycInfo, EMBASE, Scopus to July 2015	Total: 17 7 longitudinal, 7 cross sectional, 3 cross-sectional from the longitudinal BIOS study (Pittsburgh Bipolar Offspring Study) Samples recruited from inpatient (2), outpatient (2), both inpatient and outpatient (4), outpatient plus other methods (6), other methods (2), ‘psychiatric clinic’ (1)	Australia, Canada, Romania, Spain, Switzerland and USA (details of numbers not available)  (Papers from other countries may have been included but only these were listed)

Authors Publication date	Main research question(s)/aim(s)	Databases and final search date Other sources (Search terms in English only unless stated)	Number of studies Study designs Sample origins	Countries of origin of the studies included in the review
Eyden et al 2016	<p>What are the psychopathological and psychosocial outcomes for offspring of mothers with borderline personality pathology?</p> <p>What are the mechanisms (parenting or mother/offspring characteristics) underpinning associations between maternal borderline personality pathology and offspring outcomes? (Two other questions were not relevant for our review)</p>	<p>PsycInfo, PubMed, EMBASE Web of Science, Scopus, ASSIA 1980 to July 2015</p> <p>Manual searching of the journals: <i>Journal of Personality Disorders</i>, <i>Personality Disorders: Theory</i>, <i>Research and Treatment</i> Jan 2010 to July 2015</p> <p>Reference lists were also searched</p>	<p>Total: 33 (although a 34<sup>th</sup> paper by Macfie and Swan (2009) appears in the Eyden et al. (2016) narrative synthesis</p> <p>8 cross sectional, 4 longitudinal, 21 case-control</p> <p>Samples: 15 community 10 clinical 4 community and clinical 4 not specified beyond 'high risk' (overall 12/33 studies involved 'high risk' samples not otherwise specified)</p>	<p>Studies were from USA (n=15, 45%), Australia (n=6, 18%), UK (n=4, 12%), Germany (n=3, 9%), Canada (n=3, 9%), France (n=1, 3%) and China (n=1, 3%)</p> <p>NB Does not equal 100% due to rounding.</p>
Petfield et al 2015	<p>What difficulties are experienced by children of mothers with borderline personality disorder?</p> <p>(Another question was not relevant for our review)</p>	<p>PsycINFO and Medline up to July 2014</p> <p>Reference lists were searched 8 authors were contacted</p>	<p>Total: 17 - all described as cross sectional in Petfield<sup>1</sup></p> <p>Samples' sources are not detailed in Petfield</p>	<p>No geographical restrictions imposed; country of each included sample not stated</p>

<sup>1</sup> Petfield et al: All 17 included studies are also in Eyden et al, but only 16 are described in Eyden et al's tables; 12 only are considered by Petfield et al to report child outcomes, although 13 appear to include child outcomes. All 17 studies are described as cross sectional in Petfield et al, but only 1/17 (Herr, Hammen and Brennan, 2008) are described as cross sectional in Eyden et al, who labels the remaining studies (except for Macfie & Swan, which does not appear in their table), as case-control. The reason for the difference in labelling of studies as cross sectional versus case-control is unclear.

**Table 2.3: Offspring outcomes when a parent experiences major psychiatric disorder: sample descriptions and offspring outcomes descriptions**

Authors Publication date	Parental gender	Parental diagnosis	Offspring gender	Offspring age	Offspring outcomes measured	Offspring outcome measures Data sources
Rasic et al 2014	5/33 studies mothers only  28/33 studies - not specified	Schizophrenia or similar psychoses  Bipolar affective disorder  Major depressive disorder	1 study - daughters only  32 studies sons and daughters	Target: mean age of 10 years or more  Actual: mean age of 10 years or more	Diagnosed psychiatric illness or disorder  Excluding: - minor depression - bipolar spectrum disorder	All 33 included data directly from offspring All 33 studies used standardised interviews
Goodday et al 2017	10/54 studies - mothers only  44/54 studies - not specified	Any type of parental psychopathology according to ICD <sup>1</sup> /DSM <sup>2</sup> criteria or parental suicide related behaviours <sup>3</sup> (SRB)	1 study stratified for gender  1 study sons only  45 studies sons and daughters  7 studies gender unspecified	Target: 0 to 25 years  Actual: mean age <25 years in all studies but in 14 (26%) studies upper age limit >25 years	Suicide related behaviours <sup>3</sup>  Included: - severity of ideation - planned/unplanned attempts - lethality of attempts	38 studies included information directly from the offspring (+/- other sources) 12 studies only used offspring medical records/ICD <sup>1</sup> codes or cause of death registries 2 studies only included information about the child from parent/caregiver 2 studies used the SSAGA <sup>4</sup> , which is for adults so it is likely it was parent-rated, given the offspring age ranges (7-14 years in one study, 12-26 in the other).  50 studies used at least one structured measure. It was unclear how structured data collection was in 2 studies with data collected from the child and in 2 studies which relied solely on medical records

Authors Publication date	Parental gender	Parental diagnosis	Offspring gender	Offspring age	Offspring outcomes measured	Offspring outcome measures Data sources
Connell and Goodman 2002	53/127 <sup>5</sup> studies- mothers only  19/127 <sup>5</sup> studies - fathers only 55/127 <sup>5</sup> studies- mothers and fathers	'Parent mental health problems': a) alcohol/ other substance abuse or dependence b) depression c) anxiety d) schizophrenia e) anti-social personality disorder f) bipolar disorder g) mixed, including symptoms or ratings of mental distress.	22/127 <sup>5</sup> studies sons only  105/127 <sup>5</sup> studies both sons and daughters <sup>6</sup>	Target: ages 2 to 18 years  Actual: mean age ranged from 1.70 to 17.50 years Overall mean of 9.37 years (SD 3.97 years)	'Childhood internalising behaviour problems': <i>Symptom ratings</i> of -depressed mood -anxiety - social withdrawal <i>Diagnoses</i> of -childhood depression - anxiety disorders  'Childhood externalising behaviour problems': <i>Symptom ratings</i> of - aggression - conduct problems - delinquency <i>Diagnoses</i> of -conduct disorder -oppositional defiant disorder - ADHD	<i>Child symptoms of internalising behaviour problems:</i> 35 studies collected data from the child, 17 used 'combined sources' <sup>7</sup> . Other studies collected data from parent(s) or teacher(s).  <i>Child diagnoses of internalising behaviour problems</i> 38 studies collected data from the child, 23 studies used 'combined sources' <sup>7</sup> . Other studies collected data from parent(s) or 'chart review(s)'.  <i>Child symptoms of externalising behaviour problems:</i> 11 studies collected data from the child, 21 studies used 'combined sources' <sup>7</sup> . Other studies collected data from parent(s) or teacher(s).  <i>Child diagnoses of externalising behaviour problems:</i> 7 studies collected data from the child, 47 studies used 'combined sources' <sup>7</sup> . Other studies collected data from parent(s) or 'chart review(s)'.  No information on how offspring outcomes were measured - structured/unstructured

Authors Publication date	Parental gender	Parental diagnosis	Offspring gender	Offspring age	Offspring outcomes measured	Offspring outcome measures Data sources
Mendes et al 2011	Mothers only	Depression	3/30 studies daughters only  27/30 studies sons and daughters	Target: 6-12 years  Actual: 1-17 years	Childhood depression	21 studies collected data directly from the child using questionnaires/structured self-report assessment/ semi-structured interview, using a schedule, with the child (+/- separate interview with the parent) 1 CBCL <sup>8</sup> (parent report) and SDQ <sup>9</sup> (responder not specified) 3 Various structured tools (responder unspecified) 5 various structured tools (parent only responder)  All 30 studies used at least one structured tool
Lau et al 2017	4/17 mothers only  4/17 mothers and fathers 9/17 not stated	Bipolar I Bipolar II Schizoaffective disorder	1 study sons only  16 studies sons and daughters	Target: 2-30 years  Actual: 2-30 years	Psychiatric disorder diagnoses  Other emotional and behavioural outcomes	All 17 studies used a standardised diagnostic interview with the child +/- others  CBCL <sup>8</sup> was used to rate offspring internalising/externalising behaviours
Eyden et al 2016	Mothers 33 studies	Emotionally unstable personality disorder	1 study daughters only  1 study sons only  31 studies gender not specified	Target: unrestricted  Actual: 2 months to adulthood (defined here as 19+ years)  No mean child age given	Psychiatric disorder: - diagnoses - symptoms  Psychosocial outcomes: -Self-esteem -Interpersonal -Home environment	15 studies collected data directly from child - interview/ questionnaire or direct observation/experiment 5 studies child data only from other sources 2 studies unclear from whom data was collected 11 studies no offspring outcomes specified  32 studies used structured tools 1 retrospective case record review, tool unspecified



Authors Publication date	Parental gender	Parental diagnosis	Offspring gender	Offspring age	Offspring outcomes measured	Offspring outcome measures Data sources
Petfield et al 2015	Mothers 17 studies	Emotionally unstable personality disorder	Never specified	Target: 0-18 years  Actual: 0-18 years	Child 'difficulties', including: - cognitive - behavioural - parent-child relationships - mental health	13 studies included child outcomes - either/both: - data collected from the child - data collected through direct observation of the child e.g. video of mother-child interactions - All 13 studies employed at least one structured measure

<sup>1</sup> International Classification of Mental and Behavioural Disorders

<sup>2</sup> Diagnostic and Statistical Manual of Mental Disorders

<sup>3</sup> Suicide related behaviours (SRB), which here includes suicidal thoughts, suicide plans, self-inflicted potentially or actually harmful behaviour, with or without clear intent to end one's life and completed suicide

<sup>4</sup> SSAGA Semi Structured Assessment for the Genetics of Alcoholism (for adults)

<sup>5</sup> Connell and Goodman report having identified 134 separate samples, however to ascertain this information on offspring gender, one had to manually count the studies listed in Connell and Goodman's appendix 4, in which the current authors could only identify 127 separate studies.

<sup>6</sup> No studies in this review only included daughters. The table in the review refers to the child gender being either 'mix', 'both' or 'boy' but it was not clear to the current authors what the difference is between 'mix' and 'both' was and we have considered these to both represent samples which included sons and daughters.

<sup>7</sup> It is unclear if one of these sources was the child

<sup>8</sup> CBCL Child Behaviour Checklist (parent-report)

<sup>9</sup> SDQ Strengths and Difficulties Questionnaire



### **2.3.3 Results**

#### *2.3.3.1 Methodological comparability of included reviews*

Review questions, methods, and thus the nature of included studies varied (tables 2.2 and 2.3). Of the 291 unique papers in the reviews, published between 1974 and 2017, just 17 were common to the two reviews of offspring of mothers with emotionally unstable personality disorder (EUPD) (Petfield et al., 2015; Eyden et al., 2016) and only five were shared across remaining reviews. Cross-sectional, longitudinal epidemiological studies, general population-based studies, clinical cohorts, case-controlled studies and convenience samples were all represented. Although all reviews included data collected directly from offspring, the extent to which this was true varied (table 2.3). Three reviews employed meta-analysis (Connell and Goodman, 2002; Rasic et al., 2014; Lau et al., 2017) and four narrative synthesis alone (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016; Goodday et al., 2017).

Reviews varied in the extent to which they considered methodological differences between included papers. Although all reviews considered moderators, mediators or confounders in narrative, just two (Connell and Goodman, 2002; Rasic et al., 2014) of the three meta-analyses statistically tested for them; they found none with significant effect, except where findings lacked confidence due to small sample sizes and subgroup heterogeneity. Limitations reported narratively included a lack of clarity on recruitment methods or on diagnostic comorbidities (Lau et al., 2017), risk of bias – for example, studies measuring offspring exposure to parental psychopathology retrospectively (Goodday et al., 2017), reliance on a single data source (Mendes et al., 2011), predominance of cross-sectional study design and over-dependence on the parent for information about the child (Petfield et al., 2015; Eyden et al., 2016).

I aimed to cover all forms of parent-offspring relationship, but reviews rarely specified this. Only Rasic et al. (2014), required a genetic parent-offspring relationship, and only

Connell and Goodman (2002) explicitly included biological or social parent-offspring relationships. Neither parent nor offspring gender was consistently reported (table 2.3). Although all reviews included sons and daughters, three reviews confined parental gender to mothers (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016). All reviews specified offspring age, which varied from no restrictions (Eyden et al., 2016) to a narrow focus (6-12 years (Mendes et al., 2011)).

### *2.3.3.2 Outcomes*

All reviews focussed on difficulties experienced by offspring, including psychiatric disorder (Mendes et al., 2011; Rasic et al., 2014; Petfield et al., 2015; Eyden et al., 2016; Lau et al., 2017), sub-diagnostic threshold emotional difficulties and self-directed aggression (Connell and Goodman, 2002; Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016; Goodday et al., 2017; Lau et al., 2017), behavioural difficulties (Connell and Goodman, 2002; Petfield et al., 2015; Eyden et al., 2016; Lau et al., 2017), cognitive dysfunctions (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016) and social difficulties (Petfield et al., 2015; Eyden et al., 2016) – each of which are detailed below. The only advantage, thus reported indirectly by the reviews, was an absence of disorder.

### *2.3.3.3 Offspring diagnosis of psychiatric disorder*

Only one (Rasic et al., 2014) of the five reviews examining offspring diagnosis focussed on offspring of parents with schizophrenia. These offspring were seven times more likely to develop schizophrenia than offspring with healthy parents, but were not at increased risk of any of the other six disorders examined (depression, bipolar disorder, anxiety disorders, attention deficit hyperactivity disorder (ADHD), behavioural disorders and substance misuse disorders) (table 2.4). Two reviews involving offspring of parents with bipolar disorder (Rasic et al., 2014; Lau et al., 2017) found elevated risk of all disorders tested, except schizophrenia, and one (Rasic et al., 2014) found this also for parental depression, apart from with respect to offspring bipolar disorder (table 2.4). One review

(Mendes et al., 2011) reported that most of their included studies (17/22) found an increased risk of offspring depression at ages 6-12 years when mothers were depressed. The two reviews of offspring of mothers with EUPD (Petfield et al., 2015; Eyden et al., 2016) made little reference to offspring diagnosis, but both included one study (Abela et al., 2005) of 140 children, aged 6-14 years, which found that they had increased susceptibility to depression compared to offspring of depressed mothers. One other paper in these reviews (Weiss et al., 1996) identified an increased offspring risk of ADHD at a mean age of 11-years.



**Table 2.4: Absolute rates and relative risks of psychiatric disorder(s) in offspring of a parent diagnosed with schizophrenia, bipolar affective disorder or major depressive disorder, compared to offspring of psychiatrically healthy parents, according to the two reviews which tested this (Rasic et al., 2014; Lau et al., 2017)**

Outcome of diagnosed psychiatric disorder in offspring	Parental disorder	N <sup>1</sup> (no. of offspring)	Absolute rate <sup>2</sup> (AR)	95% CI <sup>3</sup>	Relative risk (RR)	95% CI <sup>3</sup>	P value	Review authors
Schizophrenia	Bipolar	581	0.04	0.02-0.10	2.76	0.67-11.27	0.158	R <sup>4</sup>
		NA	NA	NA	NA	NA	NA	L <sup>5</sup>
Bipolar Affective disorder	Bipolar	1415	0.06	0.04-0.09	4.06	1.91-8.62	0.000 <sup>7</sup>	R
		1290	NA	NA	8.97	3.85–20.91	< 0.0001	L
Depression	Bipolar	1466	0.14	0.11-0.18	2.07	1.27-3.35	0.003	R
		1494	NA	NA	2.43	1.64–3.60	< 0.0001	L
Anxiety	Bipolar	1288	0.27	0.22-0.33	1.92	1.56-2.36	0.000 <sup>7</sup>	R
		1572	NA	NA	2.14	1.63–2.81	< 0.0001	L
Behavioural disorder <sup>6</sup>	Bipolar	1027	0.14	0.10-0.19	1.84	1.24-2.72	0.002	R
		1410	NA	NA	2.48	1.64–3.74	< 0.0001	L
ADHD	Bipolar	1234	0.14	0.09-0.21	1.62	1.23-2.13	0.001	R
		1181	NA	NA	2.59	1.87–3.60	< 0.0001	L
Substance related disorder	Bipolar	1137	0.15	0.09-0.24	1.45	1.07-1.97	0.016	R
		1033	NA	NA	1.70	1.17–2.45	< 0.05	L
Any disorder	Bipolar	1285	0.60	0.53-0.67	1.66	1.50-1.83	0.000 <sup>7</sup>	R
		1214	NA	NA	1.98	1.70–2.32	< 0.0001	L

Outcome of diagnosed psychiatric disorder in offspring	Parental disorder	N <sup>1</sup> (no. of offspring)	Absolute rate <sup>2</sup> (AR)	95% CI <sup>3</sup>	Relative risk (RR)	95% CI <sup>3</sup>	P value	Review authors
Schizophrenia	Schizophrenia	816	0.12	0.08-0.18	7.54	4.02-14.13	0.000 <sup>7</sup>	R
	Depression	266	0.04	0.01-0.11	1.52	0.63-3.64	0.349	R
Bipolar affective disorder	Schizophrenia	481	0.03	0.02-0.05	1.84	0.73-4.66	0.197	R
	Depression	553	0.03	0.01-0.13	5.03	0.90-28.18	0.066	R
Depression	Schizophrenia	740	0.15	0.09-0.25	1.31	0.78-2.20	0.312	R
	Depression	1339	0.26	0.15-0.41	2.38	1.94-2.91	0.000 <sup>7</sup>	R
Anxiety	Schizophrenia	511	0.15	0.07-0.29	0.97	0.68-1.39	0.87	R
	Depression	1298	0.29	0.19-0.43	1.78	1.41-2.25	0.000 <sup>7</sup>	R
Behavioural disorder <sup>6</sup>	Schizophrenia	69	0.29	0.20-0.41	1.90	0.81-4.49	0.142	R
	Depression	1380	0.16	0.08-0.30	1.80	1.56-2.09	0.000 <sup>7</sup>	R
ADHD	Schizophrenia	69	0.10	0.05-0.20	1.76	0.34-9.03	0.500	R
	Depression	1053	0.11	0.08-0.15	2.40	1.66-3.47	0.000 <sup>7</sup>	R
Substance related disorder	Schizophrenia	528	0.20	0.11-0.34	1.72	0.88-3.37	0.112	R
	Depression	884	0.11	0.06-0.20	1.72	1.30-2.27	0.000 <sup>7</sup>	R
Any disorder	Schizophrenia	729	0.47	0.34-0.60	1.45	1.17-1.79	0.001	R
	Depression	1273	0.57	0.46-0.67	1.64	1.40-1.92	0.000 <sup>7</sup>	R

NA 'not available' - data not presented in the review(s)

<sup>1</sup> 'N' is the number of offspring of a parent with the specified psychiatric disorder on whom the particular calculation is based

<sup>2</sup> Absolute rate (AR), so 0.12 means 12% of all offspring of a parent with the specified psychiatric illness

<sup>3</sup> CI confidence interval

<sup>4</sup> R data from Rasic et al., (2014)



<sup>5</sup> L= data from Lau et al., (2017)

<sup>6</sup> Behavioural disorder in Rasic et al., (2014) includes oppositional defiant disorder (ODD), conduct disorder (CD), and antisocial personality disorder, and in Lau et al., (2017) it includes ODD and CD

<sup>7</sup> A p value cannot actually be '0' and could only be <0.0001, however it is shown as '0' here as the data is based on that detailed in the reviews cited



#### *2.3.3.4 Offspring emotional difficulties and self-directed aggression*

All reviews except one (Rasic et al., 2014) explored offspring 'emotional difficulties', which included sub-diagnostic threshold depression, anxiety, and emotional instability, unspecified emotional problems and/or suicide-related behaviours. Five reviews (Eyden et al., 2016; Petfield et al., 2015; Connell and Goodman, 2002; Lau et al., 2017; Mendes et al., 2011) concluded that offspring are at higher risk of these when a parent has a major psychiatric disorder. One review (Eyden et al., 2016) specified a significant association between offspring problems and maternal 'symptoms' of EUPD (4 studies – Stepp et al., 2012; Barnow et al., 2013; Cheng et al., 2011; Conway, Hammen and Brennan, 2015). They cite one study (Weiss et al., 1996) as describing higher rates of personality disorder, but as offspring had a mean age of 12-years, these problems are arguably personality traits. Other studies in their review focused on, and found, higher rates of offspring 'emotional dysregulation' (Macfie and Swan, 2009; White et al., 2011a; Macfie et al., 2014; Zalewski et al., 2014) insecure attachment (Abela et al., 2005; Hobson et al., 2005; Herr, Hammen and Brennan, 2008; Gratz et al., 2014) unstable self-image (Marantz and Coates, 1991; Macfie and Swan, 2009) and suicidal ideation (Barnow et al., 2006). The overlapping Petfield et al., (2015), review similarly reported higher offspring insecure attachment (Abela et al., 2005; Hobson et al., 2005; Herr, Hammen and Brennan, 2008; Macfie and Swan, 2009), and suicidal ideation (Barnow et al., 2006). Only one study of the 34 from these two reviews was clearly reported to have found no higher risk of 'child emotional problems' (Bertino, Connell and Lewis, 2012). Emotional dysregulation in the offspring also emerged in two studies (Silk et al., 2006; Joormann, Talbot and Gotlib, 2007) in the Mendes et al., (2011) review of children of depressed mothers. Connell and Goodman (2002), in their meta-analysis, found higher prevalence of combined anxiety and depression diagnoses and sub-diagnostic symptoms. Lau et al., (2017) found significant differences in Child Behaviour Checklist scores for internalising disorders between offspring with a parent with bipolar/schizoaffective disorder (n=145) and offspring of psychiatrically well parents (n=148), drawing on three studies (Salloum and Thase, 2000; Meyer and Blechert, 2005; Wilde et al., 2014). Relevant review findings with only one supporting study are detailed in Appendices B and C.

One review (Goodday et al., 2017) focussed on offspring suicide and suicide-related behaviours. Likelihood of offspring suicide was raised if a parent had schizophrenia (Ljung et al., 2012) or had died by suicide (Agerbo, Nordentoft and Mortensen, 2002; Niederkrotenthaler et al., 2012; Cheng et al., 2014), and also in one study (Agerbo, Nordentoft and Mortensen, 2002), which examined a wide range of parental psychopathology. Offspring suicide-related behaviours (SRB) were consistently associated with parental schizophrenia, maternal suicide, maternal suicide-related actions, and inconsistently with parental affective disorder, parental personality disorder, maternal suicide-related thoughts and paternal suicide (for full breakdown of offspring types of SRB, see Appendices B and C).

#### *2.3.3.5 Offspring behavioural difficulties*

Four reviews (Connell and Goodman, 2002; Petfield et al., 2015; Eyden et al., 2016; Lau et al., 2017) included reference to offspring sub-diagnostic threshold ADHD, oppositional defiant disorder and conduct disorder, anti-social personality traits and unspecified behavioural problems. Connell and Goodman's (2002) meta-analysis found a small offspring population mean elevation of risk of 'externalising' sub-diagnostic threshold states and diagnoses with a wide range of parental psychiatric disorder(s). Lau et al., (2017) found significantly higher Child Behaviour Checklist externalising disorder scores among offspring with a parent with bipolar/schizoaffective disorder (n=145) compared with offspring of psychiatrically well parents (n=148), drawing on three studies (Salloum and Thase, 2002; Meyer and Blechert, 2005; Wilde et al., 2014). Both reviews focussing on offspring of mothers with EUPD (Petfield et al., 2015; Eyden et al., 2016) concluded that offspring were more likely to have behavioural difficulties (Jellinek and Bishop, 1991; Weiss et al., 1996; Barnow et al., 2006; Bertino, Connell and Lewis, 2012).

#### *2.3.3.6 Offspring cognitive dysfunctions*

Three reviews (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016) included offspring cognitive outcomes, encompassing thoughts, perceptions, and social cognitions, and all reported higher rates of difficulties for offspring of a parent with psychiatric disorder.

Mendes et al., (2011) report that offspring of depressed mothers have difficulty recognising 'positive bases', which was not defined, but perhaps refers to a primary attachment figure. Mendes et al., (2011) also reported that these offspring focus more on negative stimuli and show decreased flexibility in changing their focus of attention (Silk et al., 2006; Joormann, Talbot and Gotlib, 2007). Both reviews of offspring of emotionally unstable mothers (Petfield et al., 2015; Eyden et al., 2016), reported poorer offspring self-representations (Macfie and Swan, 2009), and self-perception of friendship forming ability and of their own social acceptability (Herr, Hammen and Brennan, 2008). In pre-school children, both reviews (Petfield et al., 2015; Eyden et al., 2016) reported less developed offspring theory of mind and poorer offspring recognition of emotional expressions (Schacht et al., 2013).

#### *2.3.3.7 Offspring social outcomes*

Only the two reviews of mothers with EUPD (Petfield et al., 2015; Eyden et al., 2016) explored offspring experience of home and/or school and/or work, and, between them, they identified only two relevant studies (Feldman et al., 1995; Weiss et al., 1996). Both found higher problem rates in home, school and social life compared to children of mothers with other personality disorders.

#### *2.3.3.8 Offspring outcomes not reported in the reviews*

By inference, the reviews collectively demonstrate that around half of offspring whose parent has a major psychiatric disorder remain psychiatrically well at the time of assessment. However, positive outcomes, such as possible higher offspring self-esteem from taking caring roles, were not encompassed in the reviews' questions, although review discussions sometimes indicated offspring protective factors, such as secure attachment (Gratz et al., 2014, in Eyden et al., 2016).

#### *2.3.3.9 Moderators and mediators*

Five reviews (Connell and Goodman, 2002; Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016; Goodday et al., 2017) explicitly consider the extent to which variables partly explain or 'mediate' any relationship between parental disorder and child outcomes, or the extent to which they 'moderate' any effect size found. Three reviews (Petfield et al., 2015; Eyden et al., 2016; Goodday et al., 2017) quantified examination of this and suggest that under one in five papers did so (Petfield et al., (2015) 2/17(12%); Eyden et al., (2016) 6/33(18%); Goodday et al., (2017) 9/54(17%)). Mendes et al., (2011) discuss moderators and mediators without labelling or quantifying studies which examine them, while Connell and Goodman, (2002) test for potential moderators and mediators but found sample sizes generally too small and heterogeneous for confidence in findings.

#### *2.3.3.10 Additional parental factors*

Only one review considered severity, complexity and/or chronicity of parental disorder (Mendes et al., 2011). According to two included papers (Pilowsky et al., 2006; Loeber et al., 2009), child depression was more severe when mothers experienced depression with comorbid disorders(s); another study suggested inter-relationships between maternal depression, comorbidity and maladaptive mother-child interactions (Dietz et al., 2008).

This review (Mendes et al., 2011) further reported that three (all from the longitudinal STAR\*D study) of their five papers assessing change in maternal depression found that as the mother improved, so did the child (Weissman et al., 2006; Talati et al., 2007; Pilowsky et al., 2008).

The impact of chronicity of exposure was considered – by definition in the two personality disorder reviews (Petfield et al., 2015; Eyden et al., 2016) – but also in Mendes et al., (2011). The latter concluded that, overall, there was no relationship between offspring depression and chronicity of exposure to maternal depression, although they cite one longitudinal study as reporting that child depressive symptoms worsened the longer the parent had been depressed (Campbell et al., 2009).

Two reviews (Connell and Goodman, 2002; Goodday et al., 2017) examined parental gender effects. Maternal psychiatric disorder was more strongly associated with negative offspring outcomes than paternal disorder. Goodday et al., (2017) found this in all three studies which tested for it (Lewinsohn, Olino and Klein, 2005; King et al., 2010; Kuramoto et al., 2010). Connell and Goodman (2002) found that child ‘internalising behaviours’ were more strongly associated with maternal than paternal depression ( $g=0.02$ ,  $p<0.05$ ), and with maternal than paternal psychiatric disorder overall ( $g=0.04$ ,  $p<0.05$ ), although child ‘externalising behaviours’ were not differentially associated with parental gender. They also found evidence of interaction between child age and parental gender. Younger children were more likely to have emotional and/or behavioural difficulties when mother was affected rather than father, but older children when father was affected, this applying especially to paternal depression.

Child age at the time of parental illness was specifically addressed by Goodday et al., (2017) who noted that just a third (17/54) of their studies considered timing at all, most of them retrospectively. Among the seven prospective studies, two examined child age at exposure, one (Niederkrotenthaler et al., 2012) of which found a linear trend for timing of parental psychiatric inpatient admission and subsequent offspring suicide, with a slightly stronger association when the child was younger (under 3 years OR= 2.5, 95% CI 2.0, 3.0; 3-10 years OR=1.9, 95% CI 1.5, 2.4; or >10 years OR = 2.1, 95% CI 1.8, 2.6). The

control group was randomly selected from the general population, however, these analyses did not control for type, chronicity or severity of parental illness.

#### *2.3.3.11 Offspring characteristics*

Two (Connell and Goodman, 2002; Mendes et al., 2011) of the three reviews (Connell and Goodman, 2002; Mendes et al., 2011; Goodday et al., 2017) considering offspring gender as a moderator, indicated that girls may be more vulnerable than boys, although there was also interaction between offspring gender and age, and between offspring gender and parental gender; the third review (Goodday et al., 2017) was equivocal. Mendes et al. (2011) cited six studies (Leve et al., 2005; McNaughton et al., 2005; Cortes et al., 2006; Silk et al., 2006; Kiss et al., 2007; Silk et al., 2009) as finding that older girls were more vulnerable to depression when their mother was depressed. Connell and Goodman (2002) found that girls seemed to have more externalising problems when fathers experienced psychiatric disorder. Goodday et al., (2017) report that of three studies testing for moderation by offspring gender, one reported a significant interaction between offspring gender and maternal depression on offspring suicide-related thoughts (OR 5.99,  $p < 0.01$ , girls OR 5.18,  $p < 0.01$ , boys OR 0.78,  $p = 0.78$ ) (Tsypes and Gibb, 2015), whilst two reported non-significant findings (Lieb et al., 2005; Geulayov et al. 2014).

Possible mediating effects of child cognitive, temperamental and interpersonal vulnerabilities were considered in three reviews (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016) yielding few relevant studies. Both maternal EUPD reviews (Petfield et al., 2015; Eyden et al., 2016) identified a single paper ( $n = 140$  children;  $n = 102$  parents), which found that offspring cognitive problems (rumination, negative attributions, dysfunctional attitudes, self-criticism, excessive reassurance seeking and insecure attachment) appeared to mediate between maternal EUPD and child depression (Abela et al., 2005). Mendes et al. (2011) found one study incorporating children's 'verbal competence' ( $n = 164$  dyads) (Corapci, Smith and Lozoff, 2006) and one children's temperament ( $n = 337$  dyads) (Leve, Kim and Pears, 2005), which provided



modest evidence that these were associated with more depressive symptoms in the children of depressed mothers.

The complexity of relationships was highlighted by two reviews (Mendes et al., 2011; Goodday et al., 2017), which suggested that if offspring developed psychiatric disorder, this could precipitate more maladaptive mother-child interactions, which in turn, may worsen offspring outcomes. The first of these reviews (Goodday et al., 2017) evidenced such a pathway towards suicide-related behaviours in adolescents and young adults from four supporting studies, two of which focused on our parental diagnoses of interest (Kerr, Owen and Capaldi, 2008; Hammerton et al., 2015). Although the second review (Mendes et al., 2011) included two relevant longitudinal studies (Tompson et al., 2007; Hipwell et al., 2008), pathway analyses were not done.

#### *2.3.3.12 Parenting and parent support*

Three reviews (Mendes et al., 2011; Petfield et al., 2015; Eyden et al., 2016) examined parenting style, finding that it is an important mediator. Mendes et al. (2011), found that five studies showed that ‘negative parenting’ mediates between maternal depression and the severity and duration of offspring depression (Elgar et al., 2007; Dietz et al., 2008; Shelton and Harold, 2008; Riley et al., 2009; Silk et al., 2009). Eyden et al. (2016) used the term ‘maladaptive parenting’, and found two studies evidencing its mediation of the association between maternal personality disorder and negative child outcomes (Macfie et al., 2014; Reinelt et al., 2014). Petfield et al. (2015) also concluded that the ‘few’ (unspecified) studies examining this all found evidence of a mediating role for parenting style.

Two reviews (Mendes et al., 2011; Goodday et al., 2017) considered family dynamics. One reported that ‘family functioning’ partially mediated associations between maternal depression and offspring suicide-related behaviours (Garber et al., 1998; Hammerton et al., 2016). The other found that marital conflict could be related directly to maternal depression and indirectly to child depression (Leve, Kim and Pears, 2005; Low and

Stocker, 2005; Shelton and Harold, 2008), but could also follow a pathway from maternal depression through family dynamics, affecting child emotional security and raising the risk of child depressive symptoms (Silk et al., 2006; Joormann, Talbot and Gotlib, 2007).

Three reviews (Connell and Goodman, 2002; Mendes et al., 2011; Goodday et al., 2017) considered the other parent's presence and health, with two finding offspring problems associated with single parenthood (Mendes et al., 2011; Goodday et al., 2017), and one finding no enhanced risks (Connell and Goodman, 2002). Mendes et al. (2011) observed, from three studies, that being a single mother with a 'low level of education' was associated with both maternal depression and child emotional problems (Talati et al., 2007; Campbell et al., 2009; Riley et al., 2009), and from one study that the father's presence could reduce the risk of child depression (Chang, Halpern and Kaufman, 2007). Goodday et al. (2017) cited one study showing that the risk of suicide-related behaviours among offspring of a psychiatrically unwell parent was further elevated when that parent was single (Niederkrotenthaler et al., 2012). Connell and Goodman (2002) however found no such enhanced risk and speculated that a higher risk of intra-familial conflict in intact families might balance the risk of higher exposure to the troubled parent in single parent families.

#### *2.3.3.13 Genetic factors*

Six reviews (Connell and Goodman, 2002; Mendes et al., 2011; Rasic et al., 2014; Eyden et al., 2016; Goodday et al., 2017; Lau et al., 2017) acknowledged a genetic component to offspring susceptibility to adverse outcomes, although none offered evidence or discussed heritability or genetic mechanisms at length.

### **2.3.4 Conclusions and clinical implications**

This is the first review of systematic reviews examining quantified offspring outcomes when a parent has major mental disorder. Seven high quality reviews including almost 300 studies were identified. Three general conclusions follow. First, the weight of evidence appears to indicate an increased risk of offspring psychiatric disorder or behavioural, emotional, cognitive or social difficulties. Second, such conclusions, with the exception of an increased risk of offspring psychiatric disorder, tend to be based on a small number of original studies, and thirdly, potential child strengths, such as enhanced coping skills, were not explored. Material predominantly involved dependent children, suggesting a paucity of quantitative studies involving adult offspring, although qualitative research makes no such omission (Murphy et al., 2011).

The reviews provided useful pointers for future research, highlighting individual studies which suggest the relevance of the severity of parental illness and of comorbidities. The nearest any review came to considering parental violence (other than self-harm), which may accompany these serious psychiatric disorders, was Petfield et al., (2015), which reported that children of mothers with EUPD were more likely to witness violence than children of parents with other personality disorder(s), although it is unclear who perpetrated this violence.

None of the reviews sought studies evaluating potential positive correlates of experiencing parental psychiatric disorder, although three referred to this in their discussion (Mendes et al., 2011; Eyden et al., 2016; Lau et al., 2017). There are studies of children with psychiatrically unwell parents in which the children desire recognition and acknowledgement of any positives their situation presents (e.g. Cooklin, 2010), and those demonstrating offspring protective factors (e.g. Collishaw et al., 2016), but this requires further research.

This review identifies the potential value of intervention. One review (Mendes et al., 2011) found evidence of improvements in child psychiatric disorder when the parent's disorder remitted, as demonstrated in their included papers from STAR\*D (Weissman et

al., 2006; Talati et al., 2007; Pilowsky et al., 2008), which suggests that effective parental treatment may itself have offspring benefits. Indications that parenting may mediate between parental and child disorders, highlights an opportunity for intervention, and parenting programmes are effective (Bunting, 2004; Scott and Gardner, 2015). Family processes also mediate the relationship between parental psychiatric disorder and child psychiatric disorder (Van Loon et al., 2014) or other variations in child functioning (Cummings, Keller and Davies, 2005). Simple support for offspring, such as ‘two way explanations’ about the parent’s illness did not feature in the reviews but may also be beneficial (Cooklin, 2013).

This review has several limitations. Only 22 of the 291 original studies featured in more than one of the included reviews, which presents difficulties in making generalizable findings; findings from studies focusing on offspring of a parent with first episode depression will not necessarily apply to offspring of a parent with chronic psychosis. With over 250 of the included studies only being included in one review and therefore only analysed and reported on by one set of review authors, one is reliant on those authors’ assessment of the included studies and limited to the features of the studies those authors picked out to report in their review. For example, authors of a review emphasising a developmental approach may emphasise different aspects of an included study compared to authors of a review examining prevalence of mental disorder in the offspring. It is possible that for the purposes of answering my review question some of the included studies may have captured important evidence, which was not conveyed in the reviews I included, not because of any omission but because the review authors’ aim and/or research question was slightly different in emphasis or scope to my own. Had the same study been included in several reviews the different reviewers’ perspectives may have enabled more information from the studies to be identified by me as a reviewer of the included systematic reviews. Generalizable findings were also challenged by different terms and measurements being used for potentially similar presentations. For example, ‘externalising’ presentations were variously defined, sometimes including diagnosed disorders such as Conduct Disorder, Oppositional Defiant Disorder and Attention Deficit Hyperactivity Disorder (Connell and Goodman, 2022), at other times explicitly meaning

signs or symptoms which would not meet any diagnostic threshold, and sometimes being captured in other diagnoses, such as 'disruptive behaviour disorder' in Eyden et al. (2016). However, the large number of unique original studies in this review extends the range of findings. Only systematic reviews which survived quality appraisal were included, but excluding material, even justifiably, risks loss of pertinent findings. Furthermore, the time lag between original papers being published and being included in a review, means potential loss of recent relevant evidence.

In conclusion, this review of reviews consolidates evidence indicating that offspring of a parent with psychiatric disorder(s) are at increased risk of diagnosed psychiatric disorder and/or subthreshold symptoms. It highlights that even when explicitly sought by reviews, studies rarely examined the potential moderating effects of parental disorder timing, severity, chronicity, and/or comorbidity (Mendes et al., 2011; Goodday et al., 2017), nor offspring experience in adulthood (Eyden et al., 2016). It also highlights that research questions concerning offspring social outcomes emerge readily when a parent has EUPD but less readily when a parent has mental illness. Associated features, such as violence, and mediating effects, such as parenting support and offspring protective factors, were minimally considered, although parenting style and family functioning were discussed.

Recommendations encompass exploration of why some offspring experience greater adversity, including examination of the moderating roles of aspects of parental disorder, and examination of offspring protective factors and resilience. Examination of offspring outcomes in adulthood and interest in a broader range of outcomes irrespective of parental disorder, would enable a more complete understanding of the impact of parental psychiatric disorder on offspring.

## **2.4 Parental risk to others**

### ***2.4.1 Introduction***

The second aspect highlighted in figure 2.1 is that the offspring's parent must present sufficient risk to others to warrant detention in a secure hospital. As described in Chapter 1, for a patient to be legally detained in an environment as restrictive as a secure hospital, the risk to others must proportionately warrant this. This risk to others is often encapsulated in a seriously violent index offence and this offence may have involved the child as either a victim or witness, but the fact of secure hospital detention means that the risk to others is considered to be ongoing. Any intra familial violence may have been the culmination of a long escalation of such behaviour. The offence leading to any secure hospital admission may be part of a long forensic history and the parent and child may have been separated by previous parental detentions in prison. In thinking about what angles to take in searching the literature regarding parental risk to others, I considered firstly inter-partner violence and secondly parental imprisonment. The parental imprisonment could also have been examined within the third facet of parent-child separation as it has this effect also, as captured in figure 2.1. Before turning to each of these areas it is worth noting that in relation to parental risk to others, consideration was made as to whether a separate search should be undertaken looking at the substantial literature on the effects of physical abuse on children. A decision was made not to separately explore this through an additional literature review. However, where reviews on inter-parental violence extended to consider violence towards the child, this was included, and the risks posed to the child by the parent are considered throughout the thesis, and are a specific discussion point in chapter 5.

### ***2.4.2 Inter-parental/intimate partner violence***

In relation to offspring experience and outcomes in the context of inter parental violence, the search terms used were ((parent\* or mother\* or father\* or maternal\* or paternal\*) and (violen\* or aggress\* or bodily harm or assault\* or rape\*) and (inter-

parental or intimate or partner or domestic or marital or spouse) and (witness\* or expos\*)). The literature search, performed in 2017 identified a key systematic review by Kimball (2015). This was an update of a previous review by Edelson in 1999, but unlike the previous review, it did not include qualitative work. However, four pertinent themes were explored quantitatively.

Firstly, Kimball (2015) considered the harmful effects of offspring exposure to inter-parental violence. They report ample evidence of the psychological effects on offspring and specifically of an increased risk of depression, anxiety and attachment disorders. They also report evidence of an increased risk of behavioural disorders and of symptoms related to Post Traumatic Stress Disorder (PTSD) in exposed offspring. Offspring who had observed inter-parental violence more than once were also found to be at greater risk of dissociation, although this was only reported in one study (Spilsbury et al., 2007). There was also some, although weaker, evidence reported for intergenerational transmission of violence (Ehrensaft et al., 2003; Ehrensaft and Cohen, 2012 in Kimball, 2015).

Secondly, Kimball (2015) looked for new research on the effects on offspring of experiencing both inter-parental violence and physical abuse as a child, as opposed to one form of violence or the other. Again, this area had been further researched in the 15 years since the Edelson (1999) review, but the results were mixed and unsurprisingly exposure to either or both types of violence resulted in concerning findings such as an association with increased frequency of behavioural problems in the children (Silverman and Gelles, 2001) and in a separate study, increased violence as an adult (Murrell et al., 2007).

The remaining areas that Kimball (2015) sought evidence on were thirdly, for factors enhancing offspring resilience and fourthly, regarding the effect on the father-child relationship in families where the child was exposed to inter-parental violence (presumably perpetrated by the father although this was not explicitly stated in the review article). They found that neither area had been extensively researched in the 15-year period examined, with just two papers identified relating to the fourth category. The evidence found did suggest that good maternal mental health and parenting skills

were protective for offspring (Graham-Bermann et al. 2009) and that fathers involved in inter-parental violence were more likely to be experienced as less emotionally responsive by their son(s) than fathers who were not involved in inter-parental violence (Dick, 2005).

An updated scoping search performed in April 2021, to identify whether further systematic reviews in this topic area had been published, revealed several further reviews covering both quantitative and qualitative work.

Similar to the research into offspring outcomes in the context of parental mental illness, a notable proportion of the reviews considered the perinatal period, or in one case, the impact of violence towards the mother even pre-conception (Nesari et al., 2018). Systematic reviews which sought evidence of offspring outcomes in the context of violence towards the mother in the prenatal period most usually examined a narrow range of offspring outcomes, for example, birth-related outcomes (Donovan et al., 2016), offspring attachment styles (McIntosh et al., 2019; Noonan and Pilkington, 2020) and offspring internalising and externalising symptoms (Silva et al., 2018; Toso, de Cock and Leavey, 2020). One systematic review did look more broadly at mother and offspring health (Pastor-Moreno, Ruiz-Perez and Henares-Montiel, 2020) and one systematic review looked at factors which promote offspring emotional and behavioural resilience and adjustment in the context of inter-parental violence (Fogarty et al 2019), which again highlighted the importance of maternal mental health as a protective factor.

Perhaps unsurprisingly, the reviews reported evidence of an association between inter-parental violence and adverse offspring outcomes. Preterm birth and low birth weight were significantly associated with prenatal intimate partner violence, as were small for gestational age babies, although the latter was only marginally significant and there were few studies available for inclusion in this meta-analysis (n=7) (Donovan et al., 2016).

Almost three-quarters of the papers included in one narratively synthesised review (Toso, de Cock and Leavey, 2020), and a meta-analysis from another review (Silva et al., 2018) indicated a relationship between violence towards the mother in the prenatal period and increased offspring externalising and internalising problems.



The two systematic reviews and meta-analyses which examined inter-parental violence and offspring attachment styles, found that inter-parental violence was significantly associated with offspring insecure attachment. One review examined attachment between ages 1-5 years (McIntosh et al., 2019) and the other up to and including adolescence (Noonan and Pilkington, 2020). There was also some evidence that the effect size of the association was larger when measuring attachment style in infancy rather than childhood, and when using observational methods as opposed to either self-report (Noonan and Pilkington, 2020) or parent report (McIntosh, 2019).

With regards to qualitative work, the scoping search identified one meta synthesis which captured the experience of the offspring (Noble-Carr, Moore and McArthur, 2019). The narrative accounts of the young people revealed themes including fear, difficulty making sense of the violence they had experienced, powerlessness and sadness. What also came through though, which is relevant to the offspring of secure hospital patients, was that the response of services, where they were involved, could actually exacerbate the child's sense of powerlessness, when the service response felt inadequate to the child, or when the child was excluded from the information sharing and decision-making processes. When discussing how the children managed the situation, some children described talking to professionals as a 'risky' option.

#### ***2.4.3 Parental imprisonment***

The literature search terms for this area of reviewing were ((prison\* or jail\* or penitentiary or imprison\* or incarcerat\* or detention) and (child\* or son\* or daughter\* or parent\* or mother\* or father\* or maternal\* or paternal\*)). Searches in 2017 revealed a very pertinent systematic review and meta-analysis by Murray et al. (2012), which sought to examine the association, if any, between a parent being imprisoned and offspring subsequent anti-social behaviour (also encompassing non criminalised externalising behaviours), mental health problems (including internalising problems but not non-clinical issues like poor self-concept), illegal substance use and

below expected educational attainment. Further, they went on to examine the data available for any associations with parent-child dyads separated by other factors such as parental divorce or parental death.

As the Murray et al., (2012) review was the most relevant result and yet several years old I took several steps to check for recent updates. First, I checked with Prof. Murray as to whether he was undertaking an update of the published review, but he confirmed that no such update was planned. Second, I performed an update of the search in April 2021, which revealed further reviews by different authors. I discuss firstly the Murray et al. (2012) review and then the results of the updated search below.

The findings from Murray et al., (2012) were perhaps surprising in that the only prediction that could be made on the basis of a parent being imprisoned was of an increased risk of offspring antisocial behaviour - a 10% increase in antisocial behaviour in children who had a parent imprisoned compared to comparison group children. Mental health problems, substance use and academic achievement were not significantly related. The increased risk of antisocial behaviour did not remain when meta-analysis compared studies in which parent-child separation occurred only for reasons other than parental imprisonment.

The updated scoping search was performed in April 2021, and this identified that further systematic reviews in this topic area had been published, covering both quantitative and qualitative work. The most relevant additional review identified, examined children's coping strategies pertaining to their experience of parental incarceration (Thulstrup and Karlsson, 2017). The highest quality studies in this review reported child coping strategies of gaining a sense of strength through control, distracting oneself, and seeking support from friends and professionals at school. Notably, the authors also reported that a consistent finding within the review was that child coping was enhanced when the child felt involved and included in transparent discourse around the situation, in other words having at least some options for control in the situation. Child concerns around stigmatisation were also reported in 5 of the 11 included studies, and stigma and isolation were reported to reduced children's coping abilities.

A further review suggested that both internalising and externalising behaviours were more likely to occur among children who had a parent in prison than those who did not (Boch and Ford, 2018), but this was an integrative review including 17 articles and focussed on the United States (US). They did make an interesting observation that they had found a relative paucity of evidence concerning any association between parental incarceration and offspring physical health in the US. A systematic review and meta-analysis examining whether there is an association between parental incarceration and offspring body weight found no evidence of this (An et al., 2019).

## **2.5 Parent-child separation**

### ***2.5.1 Introduction***

The third key area which was identified as a factor affecting offspring of parents detained in secure hospitals was that of being physically separated from each other. The hospital admission may not have been the factor leading to the separation; this may have occurred previously, but during the hospital admission the separation is inevitable. Although this is one of the three universal factors affecting offspring during a parental detention in a secure hospital, it was not easy to discern which alternative circumstances in which parent-child separation occurs would be most appropriate to explore in the literature. Potential research areas initially considered, following on from the preliminary mapping exercise, included parent-child separation due the parent moving away from the family home for employment reasons, parent-child separation due to evacuation, parent-child separation due to parental death, and finally parent-child separation due to a parent being deployed due to military service. I will now consider each of these in turn.

### ***2.5.2 Parent-child separation due to parental employment***

Initial scoping searches conducted in 2017 indicated that the literature on parent-child separation due to the parent moving away for employment purposes was focussed on populations culturally distinct from those who are resident in the UK. For example, Filipino families, in which most family members remained resident in the Philippines while a parent moved away for work. Concern that the cultural context would undermine the validity of any comparisons led to the decision not to pursue this area of literature further.

### ***2.5.3 Parent-child separation due to evacuation of either parent or child***

A 2017 scoping search on the broad subject of 'evacuation' revealed several reviews on post disaster relocation, such as after hurricanes, floods or tsunamis. However, the trauma leading up to these evacuations was again thought to potentially confound any experiential reports or measured outcomes which might otherwise be attributed to the separation. A revised scoping search was therefore employed, which sought literature on evacuation in a preventative context, and primarily therefore, child evacuation employed during the Second World War. The experience of evacuation in this context was one of the child being relocated rather than the parent, so distinct in this way from the offspring of a hospitalised parent. Having acknowledged this, it is also possible that a child whose parent is detained in hospital may have to be relocated to another care giver if the parent was the sole carer, or if the parent's detention in hospital results in a loss of accommodation, and the research on this group of children was therefore considered to have potential relevance.

There were a number of British and Finnish cohort studies (For example Santavirta et al., 2015) which reported on this but no relevant systematic reviews. A cohort study showed that evacuation did appear to be associated with an increased risk (odds ratio of 1.7, 95% CI 1.1 – 2.6) of both mild depressive symptoms over time (score of 10 or more on the

Beck Depression Inventory) and an increased risk of more severe depressive symptoms (20% more severe symptoms 95% CI 8.7-33.1) (Pesonen et al., 2007). There was no association with overall increased risk in adulthood of inpatient admission for a psychiatric disorder among those who had been evacuated in childhood compared to those who had not, however adult women who had been evacuated in childhood were more likely to be admitted to hospital due to an affective illness than adult women who had not been evacuated in childhood (Santavirta et al., 2015). One study focussed on psychiatric inpatient admissions in the subsequent generation and although daughters of evacuated mothers had an elevated risk (hazard ratio 2.04 (95% CI 1.04-4.01), daughters of evacuated fathers, and sons with either parent evacuated, had no increased risk (Santavirta et al., 2018). There was also evidence of an increased risk of physical health problems, specifically cardiovascular problems such as hypertension and type 2 diabetes (Alastalo et al., 2009).

#### ***2.5.4 Parent-child separation due to the death of a parent***

A 2017 scoping search exploring the literature regarding offspring experience and outcomes following the death of a parent generated an impracticably large number of results, so the search was modified to include more outcome terms, including those for the offspring, with the aim of improving the specificity. The search terms used were (parent\* or mother\* or father\* or paternal\* or maternal\*) AND (death\* or bereave\* or loss\* or decease\*) AND (child\* or son\* or daughter\* or offspring\* or progeny) AND (psycho\* or education\* or cogniti\* or emotion\* or patholog\* or mental\* or soci\* or outcome\* or coping\* or advers\* or benefit\* or resilienc\* or internali\* or externali\* or conduct\* or behavio\*). Large numbers of original papers were still returned and relevant systematic review papers also. Two of the systematic reviews included a range of adverse childhood experiences, not just the death of a parent. One of these reviews indicated that the timing of events can be important (Serafini et al., 2015), and the other highlighted the importance of the father role being maintained after paternal bereavement (East, Jackson and O'Brien, 2006), which given that most secure hospital patients are men, is pertinent to our population.

The scoping search was rerun in April 2021 and identified two very recent reviews, one qualitative and one quantitative. The qualitative review was a scoping review, which focussed on adolescent daughters' experience of maternal bereavement (De Rosbo-Davies, Laletas and Round, 2021). Themes identified included first, the nature of grief, loss and mourning, including secondary losses such as loss of unconditional love and also reports of adolescents' coping mechanisms to deal with this, which included maladaptive responses such as excess alcohol intake, smoking and sex with strangers. The second theme identified was 'influences on intrapersonal development', in which they included role changes and mental health problems. Coping mechanisms again featured within this second theme but here adaptive ones were included, such as diary writing. Personal growth and increased strength were also captured here. The third theme was 'interpersonal development' and women had variously reported seeking connections with others or else feeling isolated. An absence of scope to talk about the loss of the mother within the family exacerbated daughters' feelings of disconnectedness.

The quantitative review found was a meta-analysis of the relationship between parental death in childhood or adolescence and subsequent psychiatric disorder (McKay et al., 2021). Ten of the included studies reported risk ratios, odds ratios or incidence rate ratios, and the pooled estimate from these showed that children and adolescents who had experienced bereavement of a parent had 1.2 times the odds of developing a psychiatric disorder than those who had not, but the effect size was small (pooled estimate = 1.22, CI 1.03-1.44). This meta-analysis acknowledges that different covariates were controlled for in different contributing studies, with most, but not all studies adjusting for a personal and/or family history of psychiatric disorder, and one study (Dahl et al., 2017) adjusted only for calendar time. It is difficult therefore to evaluate to what extent confounding factors contributed to observed effects.

### ***2.5.5 Parent-child separation due to parental military deployment***

The search was conducted in 2017 and updated in April 2021. The search terms used were (parent\* OR patern\* OR matern\* OR mother\* OR father\*) AND (military deployment OR military service\* OR conscription OR air force OR army OR navy). Initial searches showed that there was a significant amount of research interest in this area, which had already resulted in several systematic reviews. Given this, a review of the systematic reviews and meta-analyses conducted in this area, provided they included some offspring outcome(s), was planned. The work from the searches performed in 2017 was conducted by a student (JK) who joined the forensic psychiatry research team and who I co-supervised (with PJT). This review asked the research questions ‘what evidence is there in the research literature of child-reported responses towards having a parent in the armed forces deployed away from home? What evidence is there of adverse outcomes, both academically and behaviourally for such children, and of risk factors for these? What evidence is there of positive outcomes for such children and for resilience factors?’ (Kent et al., 2021).

**Table 2.5 Reviews examining offspring outcomes in the context of parental military deployment**

<b>Reviews identified by SA in the 2017 search and narratively synthesised by JK</b>	
Author(s) and date of publication	Review title
Card et al., (2011)	A meta-analytic review of internalizing, externalizing, and academic adjustment among children of deployed military service members
White et al., (2011b)	The impact of deployment to Iraq or Afghanistan on military children: A review of the literature
Creech et al., (2014)	The impact of military deployment and reintegration on children and parenting: A systematic review
Rodriguez and Margolin (2014)	Parental Incarceration, Transnational Migration, and Military Deployment: Family Process Mechanisms of Youth Adjustment to Temporary Parent Absence
Bello-Uto and DeSocio (2015)	Military Deployment and Reintegration: A Systematic Review of Child Coping.
Moeller et al., (2015)	The effects of military-connected parental absence on the behavioural and academic functioning of children: a literature review
Trautmann, Alhusen and Gross (2015)	Impact of deployment on military families with young children: A systematic review.
<b>Reviews identified in the updated search in 2021 by SA</b>	
Authors and year of publication	Review title
Williamson et al., (2018)	A systematic review of wellbeing in children: a comparison of military and civilian families.
Cunitz et al., (2019)	Parental military deployment as risk factor for children's mental health: a meta-analytical review
Godier-McBard et al., (2019)	Military spouses with deployed partners are at greater risk of poor perinatal mental health: a scoping review.
Veri et al., (2021)	A Scoping Review of the Effects of Military Deployment on Reserve Component Children.



This review of systematic reviews included 7 reviews, which incorporated 32 different studies (see table 2.5). Data collected from the child was only captured in a fifth of the included papers. All studies compared children of a deployed parent with children of non-deployed parents, but only two studies used children of non-deployed military parents for comparison. The remaining 30 studies used children of civilian parents for comparison, which are less well-matched groups and the demographics of the civilian children were often hard to discern from the information given in the reviews.

The reviews reported a number of negative associations for offspring when a parent was deployed. All three papers (Gibbs et al. 2007; Rentz et al. 2007; McCarroll et al. 2008), across two reviews (Creech et al., 2014; Bello-Utu and DeSocio, 2015), which studied abuse and/or neglect by the non-deployed parent, reported that there was an associated increase, perhaps due to the combined stress of the parent's separation from the deployed parent and also the greater demands on the remaining parent during this time. Parental deployment was also associated with offspring externalising behaviour problems and signs or symptoms of internalised problems. This was examined in six reviews (Card et al., 2011; White et al., 2011b; Creech et al., 2014; Rodriguez and Margolin, 2014; Moeller et al., 2015; Trautmann, Alhusen and Gross, 2015), with only Card et al., (2011) finding no association. There was also some evidence of an association between parental deployment and increased offspring mental health problems, captured in an increased frequency of outpatient psychiatric appointments (Gorman, Eide and Hisle-Gorman, 2010, cited in White et al., 2011b), of diagnoses made of stress and behavioural disorders (Gorman, Eide and Hisle-Gorman, 2010, cited in Bello-Utu and DeSocio, 2015 and Moeller et al., 2015) and of increased psychiatric inpatient admissions (Millegan et al., 2013, cited in Bello-Utu and DeSocio, 2015). Physical health correlations were less explored, but one paper in Bello-Utu and DeSocio, (2015) reported that children with a deployed parent had higher heart rates and stress scores compared to civilian parents' children (Barnes, Davis and Treiber, 2007).

Educational performance was not found to be significantly affected during parental deployment by the only meta-analysis (Card et al 2011), but Lyle (2006), cited in Moeller

et al., (2015) found that standardised test scores were affected *during* the parent's deployment but improved after the parent's return.

Only one of the 32 studies was reported to have considered increased resilience and offspring strengths as outcomes, and the authors, Heubner et al., (2007), linked this resilience to peer support. Another paper however reported that peers could respond negatively with bullying behaviour (Atuel et al., 2014). Although none of the reviews focussed on stigma, Moeller et al., (2015) reported one study (Mmari, 2009) which described children feeling 'disconnected' from their civilian peers and being discouraged from talking about their parent's deployment by their teachers.

A further scoping search performed in April 2021, demonstrated that further reviews have since been published (see table 2.5), including Cunitz et al., (2019), and Williamson et al., (2018) on parental deployment as a risk factor for child mental disorder. Less severe problems such as fear and 'behaviour problems' were also identified in a review of the children of deployed military reservists (Veri et al., 2021). The search also returned a scoping review concerning the perinatal mental health of women whose partner was currently deployed (Godier-McBard et al., 2019). This is worthy of mention given that most patients in secure settings are men and therefore their absence during a partner's pregnancy or the first year after birth is relevant.

In summary, the reviews captured child-reported responses rarely, but the evidence overall suggested an increased risk of adverse outcomes behaviourally, including markers of mental disorder, but there was no evidence of enduring academic adversity. Resilience was considered minimally but when considered was linked to peer support.

#### ***2.5.6 Parent-child separation: discussion***

The three areas of research examined in relation to the offspring experience and outcomes following parent-child separation were child separation from the parent in the preventative context of the Second World War, child separation from the parent due to

the parent's death and child separation from the parent due to the parent's military deployment. The latter of these was the most thoroughly explored.

In some regards these scenarios look quite distinct from each other, with evacuation of children from their parents for their own safety, with the intent to preserve life, appearing in contrast to the permanent loss of a parent due to the parent's death, which perhaps seems different again to parent-child separation due to parental military deployment, with the parent's life potentially at risk. However, in all of these scenarios children are separated from a parent. This is relevant given that parental detention in a secure psychiatric hospital always involves separation from their child(ren). With that in mind, parent-child separation was examined as a factor of potential importance for the development and outcomes shown in the offspring of parents detained in secure psychiatric settings.

Despite the apparent differences between children experiencing parental separation due to evacuation, parental death and parental deployment, the outcomes reported for the offspring are remarkably similar although there are some subtle and important differences. Some areas are explored more substantively in the literature on military deployment, such as the reintegration of the parent on their return, which is particularly relevant to my population of interest, but is something which would self-evidently be impossible in the context of the death of a parent and something which would likely be quite different if a child was returning to the parental home post evacuation as opposed to a parent returning to the family home post deployment.

The temporary nature of military deployment and the way this reflects temporary secure hospital admissions, enables some comparisons. For example, there is perhaps hope to be found in that some adverse associations noted during deployment, such as the dip in educational performance were ameliorated by the parent's return to the family. Possibly, with careful discharge planning and supported transitions, any parental return to the family home following a secure hospital admission may be able to buffer any negative effects of the separation during the admission. Research findings around the

reintegration after parental military deployment also highlight the nature of some of the challenges specific to this. Three of the reviews discussed how for adolescents who had taken on additional responsibility during their parent's absence, the parent's return could result in distress and anxiety as the child's role had to be renegotiated (Creech, Hadley and Borsari, 2014; Rodriguez and Margolin, 2014; Bello-Utu and DeSocio, 2015).

## **2.6 Bringing together the research regarding each facet of the offspring experience in the context of a parent's secure hospital admission**

The three facets of offspring experience relating to having a parent who has been admitted to a secure hospital – the parental psychiatric disorder, the parental risk to others and the parent-child separation, have each been explored. Although most of the searches have been scoping searches and the commentary on the resulting literature preliminary in nature, each facet has had one thorough review either identified or completed – the review of systematic reviews of offspring outcomes when a parent has a psychiatric disorder (Argent et al., 2020), the systematic review and meta-analysis of offspring outcomes when a parent is imprisoned (Murray et al., 2012) and the review of reviews examining offspring experience and outcomes when a parent is deployed, completed by JK, jointly supervised by SA and PJT (Kent et al., 2021).

Perhaps the most striking thing is the similarity in the outcomes of the research on each facet, although to an extent this reflects the questions that researchers ask, with the same sort of problems being looked for in offspring, almost irrespective of the nature of the parental situation. Evidence of outcomes was most consistent in relation to offspring internalising and/or externalising problems which were associated with each of parental psychiatric disorder, parental serious risk to others and parent-child separation.

Offspring increased risk of mental disorder was very well evidenced in the context of parental major psychiatric disorder, well evidenced in the context of interparental violence, but not in the context of parental incarceration, providing a mixed picture in the two areas I reviewed with consideration of parental risk to others. Increased risk of offspring psychiatric disorder was evidenced to an extent in the areas explored to reflect

parent-child separation. There was evidence in the context of offspring evacuation, but this was through cohort studies rather than systematic reviewing and focussed on affective illnesses. There was evidence from a meta-analysis of increased risk in the context of parental death, but this was only a small increase and confounding factors may have been to an extent accountable. The strongest evidence was from reviews examining markers of offspring mental disorder in the context of parental military deployment.

Educational achievement was examined as a possible association in the review on parental incarceration, which found no association and in reviews examining offspring outcomes in the context of parental military deployment, in which area, the only meta-analysis found no adverse association, whilst another review, which did not employ meta-analysis found an association but this did not extend beyond the period of parental deployment. Physical health effects of childhood experiences were consistently less explored but when they are explored, evidence of adverse outcomes is reported, with the exception of the lack of an association between offspring body mass and parental incarceration.

Protective factors and resilience were explored less extensively in each of the three facets of offspring experience compared to adverse outcomes. However, the importance of the child being able to talk about their experience, and for adults to talk to them and involve them in discussion came through in literature relating to parental death, parental military deployment (Thulstrup and Karlsson, 2017) and interparental violence (Noble-Carr, Moore and McArthur, 2019). There is therefore a relative neglect in the published literature for reviews to consider positive outcomes and potential areas for personal growth following adversity, although there has been some exploration of the things that the child may gain from the experience – independence, self-reliance and enhanced empathy in individual studies (Collishaw et al., 2016). By contrast, there is overwhelming

evidence to support the presence of negative effects, however exploration is required of any potential positive sequelae.

It was perhaps surprising that offspring perceived stigma featured so little in the reviews, although there was evidence of more recent interest in this area, as it was examined in one of the reviews on offspring experience in the context of parental incarceration (Thulstrup and Karlsson, 2017). One of the reasons for including the offspring experience in the context of both parental imprisonment and parental military deployment, beyond those already stated, was because they share the effect of separating the child from the parent, and both may result in the child worrying about the parent's safety, both hopefully result in parent-child reunification, yet parental imprisonment may have a significant associated sense of stigma for the child, whereas with military deployment there was anticipated to be scope for the child to have a sense of pride in the parent's actions and to feel more able to openly discuss any worries. It was notable though that teachers were reported to have told children not to speak about their parent's military deployment, which may represent institutional stigma (Mmari, 2009). There has also been a recent integrative review of stigma in relation to families where a parent has a mental disorder (Reupert et al., 2021) and to explore stigma further in relation to parental imprisonment I am a named author on a PROSPERO registered protocol for a systematic review 'to what extent do children of parents/carers who are/have been imprisoned feel stigma?' (Kalebic et al 2021). However, given that my population of interest are likely to have experienced both parental psychiatric disorder and parental imprisonment, stigma may be important to explore in this specific population too.

In thinking about the findings from the three facets of offspring experience which I have reviewed in the literature, one perspective from which to view this is that of developmental psychopathology. Developmental psychopathology considers life course development as pathways with different possible routes available over time (Waddington, 1957; Bowlby, 1973; Sroufe, 1997; Rutter & Sroufe, 2000). Within this framework, psychiatric disorder is seen as the culmination of repeated maladaptive

deviations. Different starting points can lead to the same destination (e.g. schizophrenia), a phenomenon termed equifinality, and the same starting point (e.g. insecure attachment) can lead to different destinations, known as multifinality. Experience prior to any current adversity is crucial to understanding the degree of adaptation at any point in time. This means that repeated risks are a concern but also that there are repeated opportunities for intervention and for building resilience in that person. Positive experiences that a child has can build resilience, so that even in the face of future adversity the child can maintain a positive and hopeful outlook and 'bounce back' (Sroufe, Egeland and Kreutzer, 1990). Another important aspect of developmental psychopathology models is the importance of the environment in which the individual experiences any discrete stressor, and the relationship, or transactions, between the individual and their environment (Rutter and Sroufe, 2000). Whilst thinking in developmental psychopathology terms about the outcomes for offspring of secure hospital patients, there are several aspects of the offspring experience which one might anticipate providing a potential 'junction' or series of 'junctions' at which deviations from adaptive functioning might occur – or where, even in this context, strengths might facilitate survival.

As highlighted in developmental psychopathology, the importance of prior developmental history and accumulating adversity over time is crucial for understanding psychological adaptation (Sroufe, 1997; Rutter & Sroufe, 2000). Indeed, in the ACE literature, as discussed in the introduction, there is strong evidence of a cumulative effect in that children who experience a greater number of ACEs have less favourable outcomes. Therefore, it seems reasonable to at least consider the possibility that the impact of a parental secure hospital admission on children and young people may be considerable as they are likely to have experienced multiple adversities.

Going forward, it seems important to approach further work with an open mind as to the outcomes for offspring and to consider protective and resilience factors as well as being concerned about problems which may arise. The assumption that the associations with

adverse childhood experiences will be negative reduces the scope of exploration and the narrow focus of research questions is a concern. I would suggest that more open questioning, particularly in qualitative work, around offspring experience in the future would seem beneficial, to avoid as far as is humanly possible any researcher preconceptions driving the findings, and to hear about the personal experiences of these offspring in their own words, as again this is something which has not been pursued as fully in the research literature to date. It would also be helpful to find out more about how many offspring are affected by a parental secure hospital admission by ascertaining a period prevalence over a longer period than has been obtained thus far. It is one thing to think about what the potential problems are and what features might mitigate against these, but if only a handful of children are affected that has very different implications on a societal and policy development level than if there is quite a large number of affected, and thus far hidden children.



### **Chapter 3: A period prevalence study of being a parent in a secure psychiatric hospital and a description of the parents, the children and the impact of admission on parent-child contact.**

This chapter is an amended version of a published paper, which is referenced below:

Argent, S.E., Riddleston, L., Warr, J., Tippetts, H., Meredith, Z. and Taylor, P.J. (2017). A period prevalence study of being a parent in a secure psychiatric hospital and a description of the parents, the children and the impact of admission on parent-child contact. *Criminal Behaviour and Mental Health*, 28(1), pp.85–99.

My contributions to these publications are outlined in the preface.

#### **3.1 Introduction**

In chapter 2, I explained the theoretical concerns around the potential experience of the offspring of parents detained in a secure hospital. Given the support for these concerns in the research literature regarding each of the three main facets of offspring experience, namely parental major psychiatric disorder, parental risk to others and parent-child separation, further consideration of the offspring population from a research perspective was justified. Additionally, the literature addressing parenting from within a secure hospital and the related offspring is extremely limited, even though most patients are of child-bearing age. As introduced in chapter 1, two London (England) studies (Chao and Kuti, 2009; Parrott, MacInnes and Parrott, 2015) indicate that around a quarter of men and a third of women in secure hospitals are parents. A Scottish study of similar service users (Gow et al., 2010) found a third of patients to be parents over a 5-year period. Chao and Kuti, (2009) collected data by questionnaire from two medium secure units at

one point in time, on offspring aged 0 to 18 years inclusive, so legally some may have been adults, but the age range of offspring identified in the study was not given. Parrott, MacInnes and Parrott, (2015) examined the point prevalence of parenthood in one medium secure hospital, on one day, in 2010. However, the focus of further exploration was on dependent child/parent pairs who remained in contact during the parent's admission and at the time of the study. Parrott, MacInnes and Parrott, (2015) found that two-thirds of mothers (67%) and nearly a quarter of fathers (23%) were in contact with at least one dependent aged child. This was similar to findings reported in Chao and Kuti (2009), who found that 58% of the mothers and 32% of fathers of children aged 0-18 years had any contact with them. Parrott, MacInnes and Parrott, (2015) provided the age range of dependent children who were in contact with their detained parent, which was 1 to 12 years – age ranges for other offspring were not given. Parrott, MacInnes and Parrott, (2015) did include adult aged offspring when calculating the point prevalence of parenthood, however only 2 of the 33 parents were reported to have only adult aged children. Parent-patient ages were not given, so it is hard to understand if this might be expected or not. However, the median age for both men and women in the hospital was 34-years.

Parrott, MacInnes and Parrott, (2015) also conducted a qualitative study which highlights some of the complexities around trying to maintain a parent-child relationship whilst the parent is detained in a secure hospital. They found that the combined stigma of psychiatric illness and a criminal record rendered some parent-patients unwilling to contact their children, even though they regarded parenthood as central to their identity. Although one cannot know what the child's understanding was around this decision on the parent's part, awareness that parents feel compelled to make such difficult decisions adds further weight to the need to find out more about both the parent's situation and crucially, that of their children.

As a starting point to try and ascertain further information on the offspring population I conducted a 9-year records survey of a complete secure hospital admissions cohort. This captured the full cohort of patients at this regional unit since it opened at the current premises. Nine years provided almost twice the length of the only previous period, as

opposed to point, prevalence study, and unlike Gow et al. (2010), which provided the 5-year prevalence figure, this study focused on this area. This study therefore enabled a more reliable estimate of the scale of the experience of having a parent detained in a secure hospital as it related to an entire cohort of one of only two NHS medium secure hospitals in Wales. This 9-year period prevalence produced a more stable estimate given that small populations can fluctuate, and this was particularly relevant in the context of there being a maximum of 64 patients detained in this secure hospital at any one time, of which less than a fifth are women. This records survey also enabled the first examination of the characteristics of parent-patients, compared to childless-patients, and examined whether there were features of this group which might inform understanding of the offspring experience. Finally, the survey also examined any changes in the presence or absence of contact between parent and child in the year before and the year after the parent's admission.

### **3.2 Aims**

My aims were to find the prevalence of parenthood in a 9-year admissions cohort from one regional secure hospital unit, compare mental health characteristics and offending between parent-patients and childless patients and describe parent-child contact in the year before and the year after the parent's admission.

### **3.3 Methods**

The study was undertaken as a service evaluation (NHS Health Research Authority, 2016) as confirmed with the local (Abertawe Bro Morgannwg University) Health Board's Research and Development Department.

### **3.3.1 Procedure**

I conducted a retrospective records survey of the complete cohort of admissions to the South Wales (UK) regional secure hospital unit from April 2004 until December 2012.

Information was extracted from the full multidisciplinary clinical records by medical and psychology undergraduates, who were trained to code items to over 90% agreement with each other and a senior clinician (PJT). Training of the undergraduates was led by PJT and involved inter rater reliability checks by each pair of the four researchers who were collecting data between October 2011 and April 2012. Each pair rated 10 cases independently and then compared a selection of key variables to assess the extent of agreement. PJT supervised the process of assessing the level of interrater agreement and when satisfied data extraction proceeded thereafter, with one researcher per case, although PJT remained available should queries arise.

Data, which were recorded on a checklist (see appendix D), anonymized and entered into an electronic database, included personal demographics, mental health and offending history, childhood trauma and parenting status. Clinical and criminological items were chosen to give some indication of duration and persistence of the problems (e.g. age of onset), of their complexity (e.g. multiple diagnoses, evidence of difficulties already apparent in childhood) and severity (e.g. suicide related behaviours, seriousness of violence). Details of index offences and offending histories varied considerably, so seriousness of violence was coded by SA according to the Gunn and Robertson (1976) violence subscales; scores for each scale range from '0' (no violence) to '4' (danger to or loss of health or life). It was not possible to ascertain parental exposure, or lack thereof, to the full range of ACEs, however overt abuse was documented relatively consistently. Childhood trauma was therefore coded as yes/no for each of physical, sexual and/or emotional abuse.

Being a parent was defined as ever having had a biological child or stepchild. For each child, gender, age and any special needs were recorded, together with the nature, frequency and duration of parent-child contact in the year before and the year after the parent's admission. For children under 18 years (dependent children), data was also collected on legal parental responsibility over the same periods and on who was the child's primary carer.

### ***3.3.2 Planned analyses***

Categorical variables were compared between any two patient groups – for example, parent-patients and childless patients - using chi-squared ( $X^2$ ) statistics or, if the cell size fell below 5, Fisher's exact test (FET). Where data were missing for an analysis, the sample size for that analysis is specified. For continuous variables, means were calculated for each group and compared by either an ANOVA, if the data met parametric requirements, or with a Mann-Whitney test if non parametric analysis was required. Significance was set at  $p < 0.05$ . I used SPSS version 20 for analyses.

Subgroup analysis then explored any changes over time in parental responsibility or contact for different dependent child/parent-patient pairs, from the 12 months pre admission, to 12 months post admission. The frequencies of possible contributory variables present in each pair were then examined, for example child age or gender, and parental psychiatric or violence histories. If parent-patients had more than one dependent child, and the parent appeared more than once, this was allowed, as I was interested in the possible effects of mental disorder or offending on the dyad.

### **3.4 Results**

#### ***3.4.1 Prevalence of parenthood***

One hundred and sixty-nine people were admitted during the 9-year period. Four patients' characteristics rendered them potentially identifiable, and they were thus excluded, leaving a sample of 165 (27 women; 138 men). Nearly half (76, 46%) of the patients were parents; 17 (63%) women and 59 (43%) men. About two-thirds of the mothers (11, 65%) and fathers (41, 69%) had at least one dependent child.

#### ***3.4.2 Comparison of the characteristics of the parent-patients and childless parents***

Almost all patients were White (144, 87%) and UK born (155, 94%). At the time of admission, parent-patients were older (mean 40, standard deviation [SD] 11.9; median 35, range 18-77) than childless patients (mean 33, SD 9.6; median 33, range 18-65, Mann-Whitney U = 2067, Z = -3.94, p = <0.001). Employment at the time of admission was uncommon with only 18 (11%) of 161 patients employed (11, 15% parent-patients, and 7, 8% childless-patients); one patient was a student and two were retired.

At the time of admission, 11(15%) parent-patients but no childless-patients were married. A lifetime history of marriage was more likely among parents (35, 47%) than childless patients (3, 3% n=162, FET, p<0.001).

**Table 3.1: Patients' living arrangements immediately prior to their admission**

Patient living arrangements at onset of current detention or index offence	Fathers		Childless men		Total (men)		Mothers		Childless women		Total (women)	
	N	%	N	%	N	%	N	%	N	%	N	%
Living alone	14	25	29	40	43	33	2	12	2	25	4	16
Living with one or more dependent aged child only	2	4	0	0	2	2	3	18	0	0	3	12
Living with one or more adult aged child only	1	2	0	0	1	1	0	0	0	0	0	0
Living with children of adult age and of dependent age	0	0	0	0	0	0	2	12	0	0	2	8
Living with a partner	17	30	1	1	18	14	3	18	0	0	3	12
Living with other(s) in domestic accommodation	10	18	19	26	29	22	3	18	3	38	6	24
Living with others in institutional accommodation <sup>b</sup>	13	23	23	32	36	28	4	24	3	38	7	28
Total with/without children (%)	57	102 <sup>a</sup>	72	100	129	100	17	102 <sup>a</sup>	8	101 <sup>a</sup>	25	100

<sup>a</sup> total is not 100 due to rounding

<sup>b</sup> includes hostel accommodation

**Table 3.2: Patients' psychiatric history**

Characteristic	Fathers		Childless men		Total		Mothers		Childless women		Total	
	N	%	N	%	N	%	N	(%)	N	%	N	%
Previous psychiatric treatment in adulthood												
None	9	16	7	9	16	12	4	27	0	0	4	16
Outpatient only	4	7	6	8	10	7	0	0	1	10	1	4
General inpatient	17	29	23	30	40	30	5	33	2	20	7	28
Medium or high security admission	28	48	41	53	69	51	6	40	7	70	13	52
Totals	58	100	77	100	135	100	15	100	10	100	25	100
Child psychiatric involvement												
Child psychiatrist/psychologist input	8	14	31	42	39	30	7	44	3	38	10	42
No child psychiatrist/psychologist input	49	86	42	58	91	70	9	56	5	63	14	58
Totals	57	100	73	100	130	100	16	100	8	101 <sup>d</sup>	24	100



Characteristic	Fathers		Childless men		Total		Mothers		Childless women		Total	
	N	%	N	%	N	%	N	(%)	N	%	N	%
Psychiatric diagnoses												
Psychosis only	28	47	37	47	65	47	6	35	4	40	10	37
Personality disorder only	3	5	5	6	8	6	1	6	1	10	2	7
Mood disorder only	11	19	3	4	14	10	3	18	0	0	3	11
Psychotic illness and personality disorder	9	15	18	23	27	20	4	24	2	20	6	22
Psychotic illness and mood disorder	1	2	4	5	5	4	0	0	0	0	0	0
Personality and mood disorders	1	2	5	6	6	4	3	18	2	20	5	19
Psychotic illness, personality and mood disorders	1	2	5	6	6	4	0	0	1	10	1	4
Totals	54	92 <sup>a</sup>	77	97 <sup>b</sup>	131	95 <sup>c</sup>	17	100	10	100	27	100
Co-morbid substance misuse	34	58	47	59	81	59	5	29	8	89	13	50
No co-morbid substance misuse	25	42	32	41	57	41	12	71	1	11	13	50
Totals	59	100	79	100	138	100	17	100	9	100	26	100

<sup>a</sup> Does not equal 100 as 4 (7%) still under assessment and 1 (1%) had only substance use disorder; percentage 101% due to rounding.

<sup>b</sup> Does not equal 100 as 1 (1%) still under assessment and 1 (1%) only substance use disorder; percentage 99% due to rounding.

<sup>c</sup> Does not equal 100 as 5 (4%) still under assessment and 2 (1%) only substance use disorder.

<sup>d</sup> percentage does not equal 100 due to rounding

Table 3.1 shows the patients' pre-admission living arrangements. Most had been in the community, whether parents (57, 74%) or not (54, 68%). Nearly half of those in the community were the only adult in the household (52, 47%). Despite the absence of support from another adult at home, two fathers and three mothers had one or more dependent children residing with them. Parent-patients were more likely (20, 27%) than childless patients (1, 1%) to have been living with a partner up to admission (n=156, FET,  $p<0.001$ ).

Table 3.2 shows differences in psychiatric history between fathers and childless men and between mothers and childless women. Where sex differences were apparent, this is reported in the text, otherwise comparisons in the text are simply for parent-patients and childless-patients. Most patients, regardless of parent status, had previously received psychiatric care (parents: 60, 82%; childless 80, 92%); about half of each group had had a prior secure hospital admission. Parent-patients (15, 21%) were, however, less likely than childless-patients (34, 42%) to have used psychiatric or psychological services as children ( $X^2 = 8.13$ , n=154,  $p=0.004$ ). When fathers and mothers were analysed separately (table 3.2), this difference held only for fathers ( $X^2 = 12.32$ , n=130,  $p<0.001$ ; mothers, n=24, FET=1). It was however, unclear from the records available whether psychiatric morbidity had been present in childhood for the parent-patients but gone unrecognised thus presenting a missed opportunity, or if the parent-patients truly had adult onset psychiatric disorder.

Parent-patients (49, 64%) were less likely than childless-patients (71, 80%) to have psychosis (n=165,  $X^2 = 4.84$ ,  $p=0.028$ ) or diagnostic comorbidity other than substance misuse disorders (parent-patients 19, 25%; childless-patients 37, 42%; n= 165,  $X^2 = 5.02$ ,  $p=0.025$ ). The groups were similar in their substance misuse histories (parent-patient users 39, 51%; childless patient users 55, 63%; n=164;  $X^2 = 2.09$ ,  $p=0.15$ ). Again, however, there was a gender effect. Mothers were less likely to have misused substances than the childless women (n=26, FET  $p=0.01$ ) or fathers (n=76,  $X^2 = 4.21$ ,  $p=0.04$ ).

Over half of the patients (96, 60%,  $n=160$ ) had suffered childhood abuse, irrespective of parental status. Among patients abused in childhood, however, fewer parent-patients were documented to have experienced emotional abuse ( $n=96$ ,  $X^2= 4.06$ ,  $p=0.04$ ).

Parent-patients (31, 41%) were less likely than the childless-patients (63%) to have self-harmed ( $n=164$ ,  $X^2 = 7.71$ ,  $p=0.006$ ) (Table 3.3). When men and women were examined separately, this was true only of the men ( $n=137$ ,  $X^2 = 8.17$ ,  $p<0.001$ ). Acts regarded as suicidal did not significantly differ between parent-patients (45, 60%) and childless patients (43, 49%).

Parent-patients and childless-patients had similar violence histories before the index offence (Table 3.3), but parent-patients' index offences were more likely to have been seriously violent ( $n=158$ ,  $X^2 = 5.42$ ,  $p =0.012$ ) and index victims more likely to have been related/known to them ( $n=131$ ,  $X^2=5.91$ ,  $p=0.015$ ). Most patients (125, 76%) had never hurt a child but, while this was consistently unusual among men (fathers 13, 22%: childless men 15, 19%), mothers (10, 59%) were more likely to have done so than childless women (1, 10%; FET,  $p=0.018$ ), although the low number of women overall makes some of the comparisons more difficult to interpret.

**Table 3.3 Patients' offending and risk of harm histories**

Characteristic	Fathers		Childless men		Total		Mothers		Childless women		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
Risk to Self												
Previous/current self-harm	21	36	47	60	68	50	10	59	8	80	18	67
No previous/current self-harm	38	64	31	40	69	50	7	41	2	20	9	33
Totals	59	100	78	100	137	100	17	100	10	100	27	100
Past suicidal acts	34	59	36	47	70	52	11	65	7	70	18	67
No past suicidal acts	24	41	41	53	65	48	6	35	3	30	9	33
Totals	58	100	77	100	135	100	17	100	10	100	27	100
Risk to others												
Aged +/- 17 at 1 <sup>st</sup> conviction	24	44	39	53	63	50	4	27	3	33	7	29
Aged 18+ at 1 <sup>st</sup> conviction	28	52	32	44	60	47	9	60	2	22	11	46
No convictions	2	4	2	3	4	3	2	13	4	44	6	25
Totals	54	100	73	100	127	100	15	100	9	99 <sup>a</sup>	24	100

Characteristic	Fathers		Childless men		Total		Mothers		Childless women		Total	
	N	%	N	%	N	%	N	%	N	%	N	%
No prior incidents or offences against children	46	78	63	81	109	80	7	41	9	90	16	59
1+ prior offence against children	9	15	9	12	18	13	5	29	0	0	5	19
Incident against children but no conviction/charge	4	7	6	8	10	7	5	29	1	10	6	22
Totals	59	100	78	101 <sup>a</sup>	137	100	17	99 <sup>a</sup>	10	100	27	100
Life critical index offence violence <sup>b</sup>	33	57	31	40	64	47	09	60	2	25	11	48
Low to moderate index offence violence <sup>c</sup>	25	43	46	60	71	53	6	40	6	75	12	52
Totals	58	100	77	100	135	100	15	100	8	100	23	100
Highest rest of lifetime violence – life critical <sup>b</sup>	40	68	19	24	59	47	4	25	2	20	6	23
Low to moderate rest of lifetime violence <sup>c</sup>	19	32	59	76	68	54	12	75	8	80	20	77
Totals	59	100	78	100	127	101 <sup>a</sup>	16	100	10	100	26	100

<sup>a</sup> Total does not equal 100 due to rounding

<sup>b</sup> GR Gunn Robertson Score of 4

<sup>c</sup> GR Gunn Robertson Score of 0-3

### ***3.4.3 Childless patients***

Only eight records were found which indicated that a patient's childless status had ever been discussed with them.

### ***3.4.4 The children***

The 76 parent-patients had 157 live children between them (83 sons, 67 daughters; 7 gender data missing). Ninety-four (60%) children were under 18 years (dependent) at the time of the parental admission; 56 (36%) were adults (missing data: 7). Data were available on the health of 130 of the children. Twelve (9%) had special educational or health needs documented within the records (4 with autistic spectrum disorders, 2 epilepsy, 2 born dependent on substances, 1 ADHD and Tourette's syndrome, 1 serious mental illness, 1 learning disability, and 1 was registered blind).

### ***3.4.5 Parental responsibility and primary caregivers***

In the year before admission, 11 mothers had 25 dependent children between them; eight of these mothers had had parental responsibility (four for one child each, two for two children each, two for three children each). Eight of these 14 children had had no other legal guardian, although two of the eight had already been with another relative and remained so. Of the 6 children whose mother's admission meant a change of household, two subsequently lived with their father, three with another relative and one was placed outside the family. Only one mother retained parental responsibility in the post-admission year. The 11 children of the other three mothers had already been placed elsewhere.

Four of the 6 children for whom the mother-patient had shared parental responsibility had been living with both parents prior to the mother's admission and were parented by the father after the mother's admission. One of the 6 children was parented only by the mother before her admission, despite the shared parental responsibility, and this child was also subsequently cared for by the father. The remaining one of the 6 children had been separated from both parents before the mother's admission, again despite the shared parental responsibility.

Among the 11 children for whom the mother had no parental responsibility in the pre-admission year, nine had been in their mother's primary care earlier in their lives; eight of these nine children were adopted, being adopted or in foster care during the pre-admission year and one was with another relative. The two children who had never had their mother as a primary carer were also in the process of being adopted.

Forty-one fathers had 69 dependent children between them. A minority of fathers had had parental responsibility (11, 27%; missing data 8) for 18 children between them, in the pre-admission year, a rate significantly lower than for the mothers (8, 79%;  $n=52$ , FET  $p=0.011$ ). Further, the fathers had always shared parental responsibility and none retained it after admission. For 11 of these 18 children the mother maintained responsibility after the father's admission, one child became of adult age and one had been accommodated away from both parents before and after the father's admission (5 cases unknown).

Thirty-one (72%) of the 43 dependent children not under paternal responsibility in the year before their father's admission had never had him as a primary caregiver. In the year before father's admission, mother had been the primary caregiver for most of these children (30, 70%); four (9%) had been adopted, three (7%) were with other relatives and 6 were unknown.



### **3.4.6 Parent-child contact**

Table 3.4 shows stability and change in parent-child contact for the 123 child-parent pairs for whom there was adequate contact information. There were missing data for only 11 (12%) of the dependent children but records were less complete for the adult children (16, 29% missing data). Although the proportion of missing data relating to the dependent children was manageable in terms of analysis for the study it was still a concern in terms of possible missed safeguarding issues. In most pairs (102, 83%) contact status was unchanged, but this reflected persisting separation for nearly a third of this group (37, 30%). Nearly half (14, 48%) of the dependent children who had been living with the parent-patient prior to his or her admission lost *all* contact with the parent after his/her admission for at least a year, but no adult children who had been living with a parent did so. Considering only the 41 parent-child pairs living together in the year prior to admission, this was a very significant difference (FET = 0.003). When dependent child-parent pairs were compared with adult child-parent pairs on having had any contact in the year prior to admission but none in the year after, the difference was also significant (FET = 0.032).

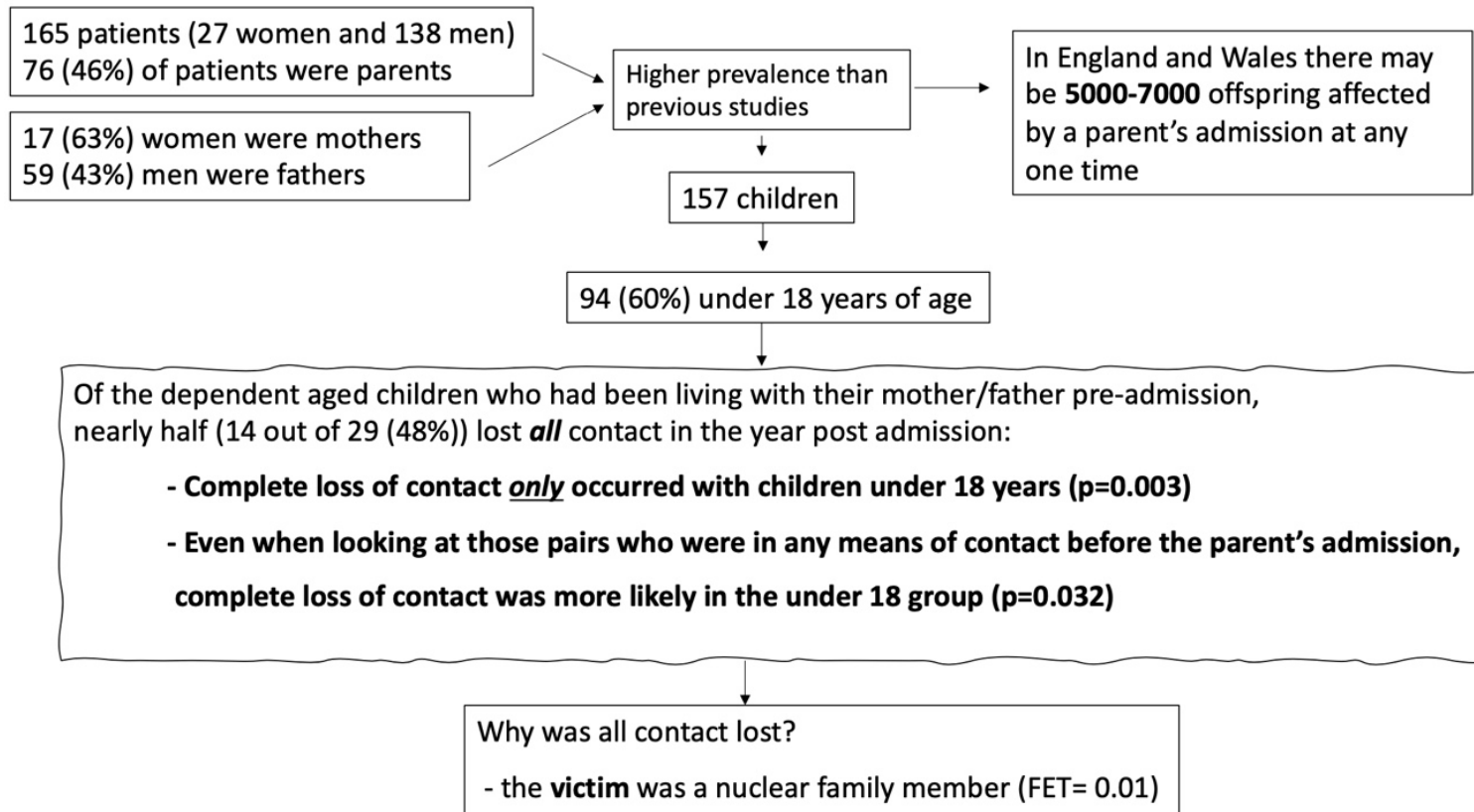


**Table 3.4: Parent and child contact before and after admission to one secure forensic psychiatric hospital**

Contact status			Parent-child pairs involving a child aged 17 years or under N=83		Parent-child pairs involving a child of 18 years or over N=40		Line totals		Overall figures for contact status (gained/unchanged /lost)	
			N	%	N	%	N	%	N	%
Contact gained/reinstated			1	1	1	3	2	2	2	2
Contact status unchanged	No contact before or after admission		26	31	11	28	37	30	102	83
	Maintained contact	Some contact before and after admission	24	29	14	35	38	31		
		Living together to some contact	15	18	12	30	27	22		
Contact lost	Living together to no contact at all		14	17	0	0	14	11	19	15
	Some contact to no contact at all		3	4	2	5	5	4		
Column totals ( <sup>a</sup> Does not equal 100 due to rounding)			83	100	40	101 <sup>a</sup>	123	100	123	100

Figure 3.1 The main findings from this cohort study

### Main findings from the cohort study



I examined the 29 dependent-child/parent-patient pairs who had been living together before the parent's admission more closely to seek possible explanations. Those patients whose victim was a nuclear family member were significantly more likely to have lost contact with their child ( $FET=0.01$ ). However, neither dependent-child age nor gender distinguished the group in which contact was lost versus that in which it was maintained. No measured aspect of parental psychiatric history (previous hospitalization, primary diagnosis of psychosis, admission diagnosis or presence of comorbidities) differed significantly between groups, nor did seriousness of the index offence, parental lifetime violence or the parent ever having been convicted of an offence against a child.

The main findings from this chapter are shown in figure 3.1. Starting in the top left, figure 3.1 captures the number and percentage of patients in the cohort who were identified as parents, and highlights that this was a higher prevalence than previously reported. To the top right is an indication that given the number of secure hospital beds for adults in England and Wales, and the average number of offspring per parent-patient, there may be 5,000 to 7,000 offspring affected at any one time. The downward arrows then direct attention to the offspring. First the number of offspring relating to the parent-patients in this cohort were identified ( $n=157$ ), of whom 94 (60%) were aged under-18-years at the time of the parent's admission. The increased risk of complete loss of child-parent contact post admission for children under-18-years of age at the time of the parent's admission is then highlighted, before the final box, at the bottom of the figure, reveals that the only identified indicator of there being an increased likelihood of complete loss of contact, is the victim of the index offence having been a member of the nuclear family.

### **3.5 Discussion**

I found a higher prevalence of parenthood among secure hospital patients than previous surveys. Allowing for the number of secure forensic hospital beds in England and Wales - probably about 6,000 – the proportion of parenthood found in this study (46%) suggests that 5,000-7,000 children could be affected at any one time by a parent's admission. I also found that parent-patients had had less diagnostic comorbidity on admission than childless-patients, but that their index offence was more likely to have involved serious violence within their social circle. All but one parent-patient who had had parental responsibility up to admission lost this afterwards. Nearly half of the under-18-year-old children who had been living with their parent experienced complete loss of contact with him/her after admission, but all the adult children living with the parent maintained contact after the parent's admission.

#### ***3.5.1 Prevalence of parent-patients***

The finding that over 40% of male and two-thirds of female secure hospital inpatients were parents, places the prevalence of parenthood at nearly twice the rates previously reported in the UK (Chao and Kuti, 2009; Parrott, MacInnes and Parrott, 2015). These studies were point prevalence surveys and, as small populations often fluctuate, documentation over the longer period of nine years probably provides a better indication of true prevalence. Regional differences are also possible. Both London studies reported more ethnic diversity than my sample and the lack of diversity within my study's sample was striking and makes the findings hard to generalise to more diverse populations. The 5-year Scottish secure psychiatric hospital study (Gow et al., 2010) might provide a closer reference sample for Wales but parenting was not the primary focus of that investigation and may thus have been underestimated. I found no evidence of parent-patients concealing children although this would be impossible to rule out altogether, and indeed, it is acknowledged that this may happen among prisoners, largely because of fears that

their children may be taken away (Mulready-Jones, 2011). My finding that proportionately more women than men were parents replicates previous findings. As I had full access to the patients' social work data as well as information from all other clinical disciplines, material about family relationships was particularly rich and I found that some patients also had important and often responsible relationships with other children, such as nieces and nephews, stepsiblings and grandchildren. I had not expected the patients to have such an extensive network of child-support roles, so had not set out to record these data systematically. Future studies should do so for appropriate, tailored support to be available when needed.

### **3.5.2 Parental characteristics**

The finding that parent-patients had less psychiatrically and socially disordered pre-admission histories than childless-patients suggests grounds for optimism that family interventions could improve circumstances for the children affected by their parent's admission as well as the parent themselves, although it is also possible that parents may have been concerned about accessing services due to concerns that they may lose custody or even contact with their child if their psychiatric struggles were known (Dolman, Jones and Howard, 2013). There is a substantial literature on the impact of mental disorder *per se* on the likelihood and stability of marriage (Breslau et al., 2011), as well as evidence of the beneficial effects of a supportive marriage on antisocial behavior (Rutter, 2012). However, it may be that patients involved with mental health services from childhood, with changing diagnoses and often several concurrent ones, particularly struggle to establish lasting intimate adult relationships. The possibly greater potential of parent-patients than childless-patients to have stable relationships has, however, to be balanced with the finding that their index offences tended to be more violent than those of the childless-patients and more likely to be directed within the family. While the latter may bring parent-patients within the scope of Andrews et al.'s (2011) risk/need/responsivity principles, which suggest that interventions are most effective with the riskiest and most engaged offenders, caution is understandable. Nevertheless, the parent's placement in a secure hospital, with health care professionals available, is a

key opportunity to work with those parents who have been recently involved in their child's care, to help the child adjust to his or her new circumstances, while maintaining immediate physical safety. It may be particularly important for a trained therapist to be available, specifically for the child, in order to develop such work, but, to date, there is little more than anecdote to guide practitioners.

### ***3.5.3 Relationship change: the relevance of child age and choice***

That older cohabiting children invariably continued contact with their parent but nearly half the dependent children did not, raises uncomfortable questions about freedom of choice among the younger children. How are the best interests of dependent children evaluated? To what extent is the view of younger children sought and taken into account? Post-admission assessment of the risks of the parent-patient to under-18 year-old children is required before contact can be responsibly authorised. The immediate post-admission phase for a person with complex problems is a time of great turmoil and it is assumed that some improvement in parental symptoms and behaviour should be achieved prior to contact, to reduce distress for the child (Adams, 2012). The child is, however, unlikely to be consulted about this. A child's distress alone has long since ceased to be an acceptable reason for barring the opposite situation where parents visit sick children in hospital (Ministry of Health, 1959). Some distress is probably inevitable, and questions should rather be about the least distressing alternative. Chao and Kuti (2009) reflected that when such children do not have contact with a parent, they may construct potentially frightening and fantastical impressions of that parent, but most previous research has been with children of prisoners (e.g. West-Smith, 2007). Again, it will be important to explore the views of children of secure hospital patients in a systematic way. In addition, it must be acknowledged that concerned family members may play a substantial role in keeping the child(ren) away from the patient, particularly where the family dynamic had become toxic during the period before admission, or especially if the index offence was against them. This too needs further exploration and understanding.



### ***3.5.4 Parents' childhood abusive experiences***

There is extensive evidence that childhood abuse is associated with later mental illness and/or behavioural disorders (for overviews, see chapters 7, 14, 15, 20 in Gunn and Taylor (eds.) 2014). In this secure hospital cohort, among patients who had suffered childhood abuse, those who had experienced emotional abuse were less likely to be parents. This may indicate a particularly toxic effect of this type of abuse on future inclination or ability to have children. Qualitative analyses of in depth interviews would help to delineate this. Danese and Widom's, (2020) findings that the risk of developing psychopathology was more strongly linked to the participant's subjective reports of childhood abuse rather than to objective records, may also be of relevance here. It was notable to find so little documented discussion with childless-patients about their childlessness and their feelings around this. Their childlessness may be relevant to how they would respond to children visiting the unit, or even for risk assessments for community visits, but it may also be an area of grief and concern to those patients.

### ***3.5.5 Strengths and limitations***

This survey includes the complete cohort of admissions to one regional secure unit over nine years, rather than point prevalence, and benefitted from social workers' extensive knowledge of patients' families and their detailed recording of this.

This study was, however, confined to clinical and social work records. In particular, I lacked narrative from the children. Although a regional centre, the sample was confined to the population of South Wales and was striking for its lack of ethnic diversity. Findings cannot therefore be assumed to be generalisable to dense urban areas with more ethnic diversity. Parent-patients were, on average, older than the childless patients, which may have been a confounding factor for some analyses. The small number of women in the survey may have precluded detection of features unique to mothers or childless women.

I only examined post-admission parent-child contact for 12 months and contact may have been subsequently reinstated. There were gaps in the data, particularly in relation to the adult children and to the frequency and duration of contact, which may have biased the findings. I also lacked data on the *quality* of parent-child contact when it occurred. It should be noted that data analysis required a range of chi squared analyses and there is a risk when conducting multiple comparisons that false positive findings will occur. However, given that my analyses were exploratory in nature, I did not correct for them as recommended by Rothman (1990; 2013).

### **3.6 Conclusions**

An issue which affects half the patients in a service – and their children – is worthy of more research attention than it currently attracts. Although many of the parent-child relationships among the patients studied had already been disrupted, for many contact was broken during the period around the index offence or at the time of the admission itself. Children who had previously been living with the parent-patient and who had more autonomy to choose whether to maintain contact with that parent on grounds of being over age 18 years invariably did so in this 9-year records survey. For children in the same position who were under 18 years and therefore did not legally have the free choice to visit their parent, half of them lost all contact in the 12 months following the parent's admission. The loss of contact experienced by nearly half of the under 18 year-olds who had been living with their parent before their admission may relate to a complex set of influences. These influences may include the paucity of research in this area, and therefore knowledge, which in turn will impact on the scope for evidence-based guidelines in this circumstance, and professionals perhaps then being unclear on the best course of action. Child protection concerns are almost certainly exerting an influence for some offspring affected given the violent nature of some of the parents' index offence and especially as the victim may have been a family member. Related to this, other adult family members involved in the child's life, such as the other parent, may hold strong views about the child maintaining, or not maintaining, contact with the parent who is detained in a secure setting, and this has been evidenced in the context of

the parent being in prison (Lockwood, 2018). Therefore, although indicators are that the parent-patients tended to have more stable lives prior to admission, which may provide grounds for optimism with family focused practice, the complex interplay of other factors, such as the likelihood of more violent index offences of parents, which were more often directed within the family, necessitates a period of detailed evaluation of needs, which takes account of the views of all parties involved.

## **Chapter 4: The voice of the offspring**

### **4.1 Introduction**

As described in chapters one and two, there is little literature to date even on the numbers of children likely to be affected by a current or previous admission of one of their parents to a secure psychiatric setting. The few relevant published papers mostly focus on the number of parents rather than the number of children. Including the publication detailed in chapter 3 (Argent et al., 2017), there are just five peer reviewed publications which consider parenting as a facet of the lives of secure hospital patients. Four of these are UK based (Chao and Kuti 2009; Gow et al., 2010, Parrott, MacInnes and Parrott, 2015; Argent et al., 2017,) and one is from the Netherlands (de Vogel et al., 2015). I have already discussed these studies in chapters 1 and 3, but will touch again on the Chao and Kuti, (2009) and the Parrott, MacInnes and Parrott, (2015) studies, which both considered parent-child contact during the parent's secure hospital admission, before summarising the key points from my papers (Argent et al 2017; Argent et al 2020) which are relevant to this chapter.

Chao and Kuti, (2009) looked at child-parent contact after the parent's admission for children aged under 18 years and found that just a third had any contact with the detained parent. Parrott, MacInnes and Parrott, (2015) expanded on this area of work and included children of any age when examining point prevalence in one medium secure hospital on one day in 2010. However, the focus of further exploration was on contact patterns for parent/dependent-child pairs, and they found that two-thirds of mothers (67%) and nearly a quarter of fathers (23%) were in contact. Parrott, MacInnes and Parrott, (2015) also conducted narrative interviews with 18 parent-patients, which highlighted the importance to patients of their role as parents. They did not however explore the views or experiences of the children.

Chapter 3 of this thesis (including Argent et al., 2017), looked at parent-child contact, both before and after admission, and includes some information on the pattern of contact across this major event. Argent et al. (2017) also examined the impact of the parental admission on any legal parental responsibility held by the parent before and after the point of their admission and, separately examined any parent-child contact. What was striking in these findings was that parent-child contact after admission, especially among those parent-child pairs who had been living together prior to the parental admission, was most likely to continue after admission if the child was aged 18 years or older. Among those who had been living with the parent prior to his/her hospitalisation, none of the adult children lost contact after the admission, but nearly half of the children under 18 years old lost all contact with their parent for at least one year after the parent's admission. Accepting the need to ensure the safety of the child and perhaps to resolve some of the initial turmoil of admission before either the parent or child can cope with a visit, it may be that this in part reflects freedom of choice on the part of the offspring as to whether to continue that contact or not. This is especially so for adult aged offspring given that child protection procedures will no longer apply in the same way and offspring capacity to make such decisions will be assumed by statutory agencies. It is not possible to know whether the younger children had any voice in whether to see their hospitalised parent, because their views were not recorded in any part of the parent's clinical record. It is notable, however, that a young man, who spoke to us as part of the feasibility work for the qualitative study which I describe in this chapter, said that his first visit to his mother was on his 18<sup>th</sup> birthday, as soon as he could choose, and that he had felt excluded before then.

In the absence of a body of literature which encapsulates the child's voice in this situation, I scrutinised the literature for any evidence of their voice regarding the various facets of their experience, those being parental major psychiatric disorder, parental serious risk to others and parent-child separation, as described in chapter 2. One notable finding, however, was how little published research captures the voice and the experience of the child, in terms of interview with, or direct observation of, the child, and none of the literature included the offspring of secure hospital patients. It is therefore

important to take steps to hear from these offspring directly about how they experience their situation and what they consider their own needs to be. This will help enable professionals to at least be aware of, and attuned to, the offspring needs when interacting with them, and hopefully also to help them to develop services to meet any of the offspring's unmet needs. Such work would also offer an opportunity to hear from offspring about their experiences of contact with their parent during the parent's secure hospital admission, and offer opportunity to understand the offspring perspective on the patterns of parent-child contact, before and after the parental admission, which I observed in chapter 3. Given the evidence of likely need among the offspring of secure hospital patients, and the absence of research evidence addressing this, a new piece of research was indicated. Given the absence of any research which considers first person accounts by offspring who have a parent who is, or who has been, detained in a secure psychiatric setting, the study was necessarily exploratory in nature and therefore a qualitative approach was required. This is described further below.

#### **4.2 Theoretical framework: Grounded Theory**

In pursuing a qualitative approach, I used a grounded theory method to inform both the main part of the interview process and the analysis of the resultant interview transcripts. Grounded theory was originally 'discovered' and described by Glaser and Strauss (1967) who sought to systematically analyse qualitative data to discover theories from the data. The original area of research interest and work from which the grounded theory approach developed pertained to the processes and experiences related to patients dying in a hospital environment (Glaser and Strauss, 1967). Grounded theory as described by Glaser (1998) necessitates that participants are asked open questions, which are designed to enable them to tell their story as they wish, uninfluenced by preconceptions or bias. In this way grounded theory particularly safeguards against researcher preconceptions influencing the data generated by requiring the interviewer consciously to put aside any preconceptions (as far as is humanly possible) (Glaser, 1998).

Grounded theory analysis of the narrative data allows a core concern and theory of resolution to emerge from the data and in this way is described as inductive. The method emphasises the importance of the researcher not forcing the data, which again requires the researcher to actively desist from imposing their own ideas and preconceptions on what emerges, and instead remain as objective as possible. The process through which this is facilitated, depends on, first, line by line coding of data categories, followed by a process called constant comparative analysis of these categories, so that higher order categories may be found in the data. This process allows the core concern and model of experience to emerge directly from what the participants have said (Glaser and Strauss, 1967).

This grounded theory analysis can only be applied to narrative data generated from open questions, however once a model has emerged from such narrative it can be 'tested'. Data from more structured sweepster questions were used for the purpose of testing the derived model in the absence of published literature relating to the offspring of secure hospital patients as detailed in earlier chapters in this thesis.

The grounded theory approach described above, which Glaser (1998) continued to uphold, is that which I have sought to take in this study, however it should be noted that Glaser and Strauss subsequently diverged in their thinking and approach to grounded theory, which became more apparent as Strauss began to work with Corbin, as demonstrated in Strauss and Corbin (1990). Whilst Glaser continued to focus on an inductive approach (Glaser, 1992), Strauss and Corbin (1990) moved towards a more deductive approach, whereby existing theory and prior experience were allowed more of a role. Charmaz was trained by Strauss and Corbin and describes 'constructing' theories rather than discovering them (Charmaz, 2006, 2014).

### **4.3 Aim and objective**

The aim is to understand the experience of people who have a parent who is, or who has been, a patient in a secure psychiatric hospital and find a theory or model of that experience that could subsequently be tested.

### **4.4 Scoping, preparatory and pre-procedure work**

#### ***4.4.1 A feasibility interview with a young adult***

Before designing the study in any detail feasibility work was undertaken. First it was important to find out whether it would be likely to be acceptable to potential participants at all and then, more specifically, whether this approach with an open question prompting unstructured reflection would be acceptable. Accordingly, the nature of the study was explored with one young man who had experienced his mother being a patient in a secure hospital. This young man was recommended for this feasibility work by the parent's social worker, a person who had known the young man for many years and was confident of his ability to talk to us and was available to sit in on the interview to offer any support to the young man if required.

After establishing the young man's own understanding of research, which was impressive - he spoke about having conducted questionnaires to seek customer views as part of a college course, relating it to that – the project being considered was briefly outlined in terms of our wanting to speak to people in his position to understand what their experience has been. When asked how one might go about this he advised to *'just ask for the story from their perspective', 'ask everything from start to finish', 'build a picture'*.



The young man was reflective on the possible advantages and disadvantages to such research. He suggested that the research *'could be of benefit to both [parent and child] and [could] involve both'*.

In terms of potential disadvantages, he spoke of the possibility of *'well, someone getting upset....'*

But he didn't feel that this should preclude the research, rather he suggested that the interviewer *'give them time..... You can tell them that it's okay'*. He was asked *'so would it be fair to say that managing distress is better than avoiding talking about these issues?'* The young man's view was *'yes, definitely'*.

The young man was also asked about the issue of age and whether it would be acceptable and appropriate to interview people younger than he was at that time. He was asked *'you're an adult now but supposing we had come to you when you were 16, would it have been okay to talk to you about these issues back then?'* He replied: *'maybe it would have been better to ask me about these issues back then – I have much more on my mind now, in some ways more stresses'*. The social worker who kindly facilitated the interview and who had known the young man for several years added that *'I can vouch for that, [he] would have been well able to participate then'*. Given this, the young man was asked *'would it have been okay to ask you to take part in research when you were 12?'* and his response was *'I welcome talking, so yes, but I'm not sure that I would have been able to say much useful – at 12 I was into monsters and explosions. The world was different when I was 12. I don't think I'd have minded talking to you, but it would have been different. I may not have answered very well, but I'd say go for it. Thinking about it, my story at 12 would have been very different. You should ask them again and again. Get the issues as they arise at each age and the issue itself'*.

This feasibility interview therefore supported the view that an interview study would be an appropriate way forward and, for this young man at least, would be considered to be potentially beneficial for him and his parent. The approach which he suggested fits with a grounded theory approach.

Although the young man interviewed expressed confidence in his own ability to have participated in any study at a slightly younger age of 16 years old, I decided to design the study to involve only adult aged offspring in the first instance. This was because, given the exploratory nature of research work with this group of people, it felt ethically appropriate to commence this with adult aged offspring. I was mindful of the sensitivities around conducting research with children who have, by definition, experienced a range of adversities. I also held in mind the complete loss of contact that nearly half the dependent offspring who had been living with their parent experienced post parental admission. Given this, and in the context of uncertainty around the contributory factors, it seemed most feasible and sensitive to start by speaking to adult aged offspring who were able to consent freely to participate. Direct work with the adult offspring as well as being important research in its own right, will also help inform potential future work involving other, younger offspring, in the same situation.

#### ***4.4.2 The interview development***

The interview was designed with the comments of the young man who participated in the feasibility interview constantly held in mind and followed the format detailed on the enclosed 'Interview Schedule' (see Appendix E).

At the beginning of the interview the participant was reminded that the interviewer had no role in the current care and treatment of the parent and that the researcher was not in a position to give any information at all about the parent or to confirm or deny any beliefs that the child may have about the parent. The interviewee was assured of the confidentiality to the research of all information given unless that information suggested that there was a risk of serious harm to any person(s), in which case that information and that alone would be conveyed to an appropriate person in the parent's clinical team or, if the participant was indicating that s/he himself posed some risk (most likely here to self) to an appropriate other, possibly to their GP. The participant's ongoing consent was confirmed before commencing the interview and their preference around whether the interview was recorded or not was also confirmed.

All the interviews were conducted and transcribed by me.

First, a few preliminary questions around the participant's age and current occupation were incorporated to yield contextual information, facilitate rapport building and settle both the interviewer and the interviewee into the interview process.

The open section of the interview was prompted with a broad, open question:

*'Please tell me about your experience of having your mother/father as a patient in a secure or forensic hospital.'*

This created an opportunity for the participant to say as much as they wished to, with only limited prompting from me – such as 'tell me a bit more about that' – aiming to avoid introducing interviewer biases.

The semi-structured section of the interview incorporated a range of sweeper questions, to try and capture the full context in which the participant had experienced is/her parent's secure hospitalisation and/or was experiencing it at the time of the interview. These sweeper questions in the semi-structured interview were not intended to generate material for the grounded theory analysis but were designed to ensure that I had a sufficiently comprehensive understanding of the participant's experience to be able to conduct preliminary testing of the model which emerged from the grounded theory analysis. The additional questions also enabled me to ask the participant about their views on potentially interviewing younger children.

The topics included in the semi-structured interview were wide ranging and I was aware that it was possible that some of the questions may have reminded participants of difficult experiences. In view of this, the participant information sheet emphasised that there was no obligation to answer any question(s) if the participant did not feel comfortable to do so, and that they could ask for a break at any time. I also emphasised this verbally to the participant before commencing the interview.

To safeguard further against any insensitive questioning, the opening question in any sub section of the semi-structured interview was deliberately broad to offer participants the option of touching loosely on it, or in more depth. Whilst follow up prompts were available to seek more in-depth information where appropriate, I remained attuned to signs of distress or discomfort from the interviewee and tailored interviews accordingly. Finally, the participant was given the opportunity to add anything further in response to another open question towards the end of the interview which asked whether there was anything else that the participant felt it was important for us to know, or which was relevant to the research, which I had not asked about explicitly. Participants were also given the option of making further contact with me if things came to mind subsequently which they felt were important for us to know. In the final section of the interview, I asked the participant about his/her thoughts on the research, including their thoughts about interviewing children under 18 years of age.

#### ***4.4.3 Developing recruitment strategies***

Recruitment was initially anticipated to be through three clinical sites: Caswell Clinic in South Wales, Bracton Clinic in South East England, and Ty Llewellyn, in Conwy, North Wales. All three sites were included in the NHS Research Ethics application and received approval. However, a key staff member left their role at the Ty Llewellyn site before the local Research and Development (R&D) office approvals had been secured for this site and, in the context of the pandemic, I was unable to visit the site to build new relationships, so this was not taken further in this research period.

Of the remaining two sites, recruitment commenced at Caswell Clinic first and was later extended to the Bracton Centre when R&D approvals were in place there. Prior to recruitment commencing, presentations were given by me, in conjunction with Pamela Taylor, to the two clinical sites in order to explain the purpose of the research and the nature of the proposed study. I was also available to meet remotely with staff at both sites if required and to answer any queries as they arose from either staff, parent-patients or potential participants. Whilst I was still working at the Caswell Clinic in a

clinical capacity, I was also able to meet in person with staff and parent-patients to discuss the research and answer any queries. I also forwarded the Participant Information Sheet (see Appendix F) and the Health Care Professionals' Information Sheet (see Appendix F) to clinicians at both sites. By the time interviewing was due to start in earnest, the pandemic precluded further face to face meetings, but I was available remotely as required. The impact of the COVID pandemic on the research is discussed in full later.

I encouraged clinical staff at the two sites to identify prospective adult aged offspring participants. Staff, if they had an existing relationship with the offspring, were asked to make them aware of the opportunity to participate in the research. If the potential participant expressed an interest in knowing more, then, through the staff member, they could forward their contact details and preferences to the research team, or else contact the research team themselves as preferred. It was essential that if staff approached offspring, that they were fully aware that the researcher was separate from the direct clinical care team of their parent and that their decision to participate, or not, would not affect any of the support or services offered to either them or their parent and that the researcher would not be talking to the parent about the interview if it took place.

If staff were aware of a patient having an adult child but the staff member did not have an existing relationship with them, then I asked them, if clinically appropriate, to make the parent-patient aware of the research and ask if I might contact their son or daughter. If the potential participant were interested to know more, the parent-patient could pass their details to the research team who could then approach the adult child directly. Staff and patients also had copies of the 'Participant Information Sheet', so they could hand this out freely if they wished. The consent form (see Appendix G) was also freely available if staff or patients wished to see exactly what participants would be agreeing to undertake.

Posters (see Appendix H) were also planned for display in the waiting and communal areas at the clinical sites so that offspring visiting a parent in the clinic could see the information and contact the research team directly if they wished.

#### **4.4.4 The ethics approval process**

Peer review by two independent experts was sought prior to submitting the project protocol for NHS Research Ethics approval. The experts contacted were not employed by any of the NHS Trusts or Health Boards involved, nor by Cardiff University. Neither reviewer had been involved in the study in any way. They were approached due to their clinical and research expertise, including within the spheres of forensic psychiatry and child and adolescent mental health. One of the reviewers approached works outside the UK, giving an international perspective. The peer reviews are included in Appendix I, whilst the protocol v 0.1 (26.09.2017), which they reviewed, follows in Appendix J. All comments made by both reviewers were carefully considered in turn by me and Pamela Taylor and amendments to the protocol were made, as felt appropriate, in v0.2 (15.12.2017) (all changes made to the protocol in the various amendments are shown in Appendix K).

Risks and problems considered prior to applying for NHS Research Ethics approval mostly pertained to safeguarding the data and steps taken to ensure this occurred. A key consideration, however, was the well-being of the potential participant. As there was so little information about potential participants, I could not be sure that they might not have mental or physical health problems of their own or indeed any other vulnerabilities. I was aware that I needed to be sensitive to this possibility, but was not approaching prospective participants as patients, but primarily as community living members of the public who happened to have, or have had, a parent in a secure hospital. During the feasibility interview, the possibility of participants becoming upset by the material being discussed was raised, but the young man's view was that this could be adequately managed by usual interview procedures, as described previously. Because of this possibility, however, I discussed extensively with my supervisors whether it would be appropriate to provide a follow up contact with participants a week after the research interview. The decision was made not to do this for several reasons. First, neither the wider research team nor I were involved in a therapeutic way with the participants and wanted to avoid any misleading inference to the contrary. Secondly, if the participant

had become distressed, then any assistance should have been available in a more timely way, such as that which their support network or general practitioner should provide. Thirdly, I thought, at worst, that there might actually be a risk of prolonging any distress by expecting the participant to return to it a week later and, at best, I would be taking more of the participant's time. Finally, from the experience of the Social Work team at Caswell Clinic, who routinely interview adult family members to gain collateral history, adults who agree to talk to them have always been emotionally robust enough to engage in discussion without becoming overwhelmed, particularly when the interviewer is attuned to any signs of emerging discomfort with the topic. An alternative approach would have been to offer a 'debrief' immediately after the interview, which was not formally offered to participants but as interviewer I did check in with them at the end of the interview and at any point at which I had any concern that they might be uncomfortable. I also kept the decision not to offer a debrief or follow up under review.

After submitting all required documents to an NHS Ethics Committee, I attended an Ethics Committee hearing in person, with one of my supervisors (Pamela Taylor). The research was approved by NHS Wales REC1 (see Appendix L), subject to minor amendments to the information sheet, mainly to inform potential participants that they would be asked some questions about their own mental health and behaviour as well as direct experiential questions. It was also approved by Research and Development departments at Abertawe Bro Morgannwg University Health Board (ABMUHB) (later Swansea Bay University Health Board (SBUHB)) and Oxleas NHS Foundation Trust (Oxleas NHS FT).

#### ***4.4.5 Protocol amendments and additional ethics approval post COVID-19***

In April 2020, when the interviewing work was starting in earnest, the COVID pandemic placed a barrier on all face-to-face research activity that was not directly COVID-related. My next steps, therefore, were to agree a way of continuing the work through remote interviews.

I submitted an ethics amendment application to the NHS Research Ethics Committee and subsequently also to the R&D offices for SBUHB and Oxleas NHS FT, together with a revised project protocol, information sheets and consent forms to enable the interviews to be conducted remotely. These revisions were considered to amount to a non-substantial amendment and were agreed by all relevant agencies. This process, however, of amending the protocol and related project documents, completing the amendment paperwork, submitting this, chasing up the outcome and then gaining confirmation from the local R&D offices that they were happy for me to proceed took in excess of 3 months. The revised project documents are available in Appendix M.

## **4.5 Methods**

### ***4.5.1 Study settings***

This was a multi-centre study that, ultimately, took place across three sites, two of which were NHS sites, and one of which was a university site. My two supervisors and I were primarily employed at the university. There was a possibility of interviewing participants on university premises if they preferred (none took that option). The NHS sites were the main recruitment sites and prospective interview sites, although I also had several options within the Health Board/Trust for interviewing offspring away from the secure unit if they preferred that. In the event, before interviewing began in earnest, the Covid-19 pandemic affected the UK and lock down and infection control procedures mandated a different approach be adopted, as discussed above.

### ***4.5.2 Recruiting the sample***

Any offspring aged 18 years or older at the time of recruitment and who had had, a parent or primary caregiver in a secure hospital was eligible. 'Primary caregiver' could include, for example, stepparent, foster parent, adopted parent; this list was indicative



and not exhaustive. The primary caregiver could have been detained in any level of security within the secure psychiatric estate i.e. low, medium or high security, although the plans for recruitment made it most likely that parent would either have currently or previously been detained under conditions of medium security. Inclusion and exclusion criteria were as follows:

#### *4.5.2.1 Inclusion criteria*

- Have, or have had, a parent/primary caregiver, detained as a patient, in a secure hospital.
- Aged 18 or over.
- Had capacity to consent.
- Sufficiently fluent in English to demonstrate capacity to consent and to participate in the interview.

#### *4.5.2.2 Exclusion criteria*

- Aged 17 or under.
- Non-English speakers.
- Unable to give informed consent.

There is no pre-determined sample size in grounded theory research, rather the sample is determined by 'data saturation', which is when no new categories of data are emerging in new interviews (Glaser and Strauss, 1967; Glaser, 1998). That said, as the NHS Research Ethics Committee required some idea of likely recruitment needed, I estimated that no more than 20 participants would be needed for the study as most data-rich grounded theory studies do not exceed this, as seen in Parrott, MacInnes and Parrott, (2015), Kalebic et al., (2020), Wells et al., (2021).

#### **4.5.3 Sampling technique**

I adopted a purposive sampling approach. In brief, I accepted any eligible volunteer as a participant for the first interview, and then tried to recruit a rather similar person for the second interview. Thereafter, every effort was made to include participants who were as diverse in themselves and their experience as possible, as this provides both maximum richness of data and hastens data saturation. The reality was that to enable participants to know about the project and participate as they wished, the order in which participants were interviewed was driven to a large extent by the order in which they confirmed their interest.

#### **4.5.4 Interview Process**

The timing and modality of the interview was agreed with the participant in advance. Participants all completed and returned consent forms by email prior to the pre-arranged session for the interview. At the time of the interview, after introductions, I recapped with the participant their understanding of the project and what it entailed and ensured their ongoing consent to take part. I would also check the participant remained happy with their decision to allow or not allow the interview to be audio recorded and reminded them that I would be taking notes throughout. Interviews commenced with a few brief questions which were expanded on or not as felt most comfortable – the aim here being to settle both the interviewer and interviewee into the interview process having moved on from confirmation of consent and other administrative tasks. The interview then proceeded with the broad open question, described verbatim before, and then, the semi structured sweep questions. Where there was time and it felt appropriate, additional questions on the interviewee's experience of the interview process and their thoughts on interviewing younger participants in the future were sought.

Had the participant appeared to be struggling at any point during the interview, they would have been offered a break or for the interview to come to a close. In face-to-face

interviews, the plan had been that I, as interviewer, would remain available to the participant to assist in any way required, with support or practical arrangements, until the participant was able to leave the building. As all interviews were ultimately conducted remotely all I would have been able to offer was to have remained similarly available to the participant until the participant's distress had subsided.

Generally, at the end of the interview, the participant's involvement came to an end. However, if the interview was unexpectedly cut short for some reason, such as internet failure, or the participant was unable to say as much as they wanted to by the end of the first interview, then the protocol provided scope for the interview to be resumed at a later, mutually convenient date. There was also scope, within the protocol, for participants to add any thoughts or reflections once they had left the interview by subsequently making phone or written contact with the team.

#### ***4.5.5 Data Analysis***

Participants were asked to allow the interview to be audio recorded but offered the option that they could talk without recording and I would take notes. In the event, all agreed to the recording. As soon as possible, but at any rate within 48 hours, I transcribed the interviews into verbatim written records of the interview.

Analysis of the transcripts was according to grounded theory methods, using only the free narrative section of the interview. Because I had added a more structured component to the interview, I allowed at least 6 weeks between transcribing the interview and analysis to reduce any bias from the more structured question and answer section of the interview. This was because I wanted to preclude as far as was possible, my awareness of the content of the participants' responses to the structured questions influencing my analysis of their responses to the unstructured section.

Analysis was conducted first with line by line coding of data to find first level categories, as far as possible choosing a key word or phrase from the narrative for each category label and providing the full quotation as supporting data.

This was followed by a process called constant comparative analysis, such that each category was compared with each other category and examined for similarities. Higher order categories were allowed to emerge from this process and then re-examined to check that they accounted for all the data. Finally, the core category or concern, which best encapsulated and explained the data was identified (Glaser and Strauss, 1967). Memos were used to help the analytical process.

The semi-structured part of the interview which followed the initial open section was used to make some preliminary tests of the model which had emerged from the analysis of the open questioning. This was achieved by comparing the model to the content of the additional material gathered in response to the more structured interview questions to ensure that this additional material was consistent with the model. Data in the form of further quotations, but here from the responses to direct questions, were utilised to this effect.

## **4.6 Results**

### ***4.6.1 Description of the sample***

Twenty-two potential participants were identified. Eight people were certainly made aware of the project, of whom four completed interviews, whilst four chose not to participate. For a further four, the parents were aware of the project and said that they would discuss the research with their child(ren), but I never heard from the children directly. This, therefore, left 10 people who were eligible to participate but as far as I know, never knew the project was underway. The twenty-two eligible potential participants identified are discussed in more detail below.

#### *4.6.1.1 The actual participants*

Four interviews were agreed and completed. The first interview was with a daughter whose father had been a secure hospital patient, as was the second, which is consistent with grounded theory methods as described previously. The third interviewee would ideally have been as different from the first two as possible, to try and expedite data saturation. In the event, the third participant was another daughter, but one whose mother had been a secure hospital patient. The fourth interview was with a son whose mother had been a secure hospital patient. Two of the participants were siblings. For three of the four offspring, their parent had moved on from conditions of medium security at the time of the interview. Participants' age ranged from 26 to 31 years old. All were UK born, although two had lived abroad in childhood, and one again as an adult. All were UK residents at the time of the interview. At the time of the interview, two were residing in Wales and two were residing in England. All were in contact with their parent-patient at the time of recruitment to the study and interview. Ideally, further interviews would have been conducted as the data was not saturated after analysis of the fourth interview. However, the project was brought to an end at this point for the PhD because of difficulties in recruiting which were related to the COVID-19 pandemic and which are discussed in full later in the thesis.

#### *4.6.1.2 Potential participants who declined to participate*

Four potential participants were aware of the research but did not take part. One son whose mother was a patient in a medium secure unit had agreed to participate but subsequently either changed his mind or circumstances prevented him from engaging with the project. Another son whose mother was a patient received the participant information sheet but did not subsequently get in touch with the team. I followed this up with the social worker who had been supporting the participant's mother and was advised that 'the mother' no longer wanted to take part in the research and that her adult son 'will not want to' either. The detail in this feedback shows how participation could be misconstrued as at the parent's discretion, and whilst this was not ethically appropriate, recruitment was hampered by the reality that my route to the offspring

was, in all but two cases, at least partly controlled by the parent-patient – this is explored further in the discussion. A third son whose mother was a patient was sent the participant information sheet through the post from the parent’s social worker but also never contacted the team. The fourth potential participant who declined to take part was an adult daughter whose father was in a secure hospital. The project was discussed with her by one of the hospital’s social workers and whilst she initially said she would think about taking part she decided not to do so in the end.

#### *4.6.1.3 Potential participants who may never have known the project was underway*

I was aware of a further 4 potential participants whose parents were made aware of the opportunity for their offspring to take part in the research, but who did not pass their children’s contact details to the research team. The parent-patients reported back to staff that they had made, or that they would make, their offspring aware, but I had no contact with the offspring regarding this and it is impossible to know therefore whether they were aware of the research or not. Clinicians working with the parents were reluctant to follow this up, given the parents’ reports that their offspring were not interested.

#### *4.6.1.4 Potential participants who never knew that the research was underway*

There were a further 10 potential participants who I identified but for various reasons described below never knew that the project was underway. For two of these potential participants, staff had tried to reach the offspring but without success.

One of these potential participant’s parent-patient had provided her Responsible Clinician with contact details for her son and was happy for him to be contacted about the research, but the clinician was unable to get hold of him, possibly due to his work commitments. I asked to take on the role of trying to get in touch with the son myself but was not forwarded his contact details. I am not sure whether the parent-patient, or the clinician, or both, had felt uncomfortable with me receiving these.

The second potential participant who staff made repeated attempts to contact was the young man who had taken part in the feasibility interview. When the study started his mother was no longer detained in a secure setting, but I was able to follow up with the mother's then care coordinator in the community. The care coordinator raised the research project with the parent-patient numerous times over a four-year period, however I was advised that his mother declined to make him aware, citing various reasons, ranging from him being troubled with personal issues, to him needing to focus on his education.

For the remaining eight offspring who would have been eligible to take part, staff felt it inappropriate to try and make the potential participant aware. One of these was the sibling of other potential participants, but as this child was not routinely in contact with the parent, and there had been some tensions in the relationship previously, staff did not mention the possibility of this child taking part, to the parent-patient, even though discussions around the other children participating took place. One potential participant was considered 'too fragile' by the Community Psychiatric Nurse who knew him well, although he was employed and had his own dependents. One participant's parent had moved on from the clinic and although this was the case for three of the four participants who completed the interview, in this instance the clinical team did not advise of any possible route to establish contact with the offspring.

For two potential participants, there were concerns from the clinical team as to the appropriateness of asking them to take part due to the extent of the trauma they had experienced in relation to the parent-patient's index offence. Although these offspring were living independently in the community and there was nothing to indicate that they would have lacked capacity to decide for themselves, the clinical team felt unable to contact the offspring about the research.

One potential participant was identified by the parent-patient's Responsible Clinician but the Social Worker who could have taken this forward never replied to communication from me to try and progress this. Finally, two adult children were known of in relation to a mother who was a secure unit patient, but the mother was not in touch with either

child and they lived abroad, so despite knowledge of the offspring's existence (which wasn't contested), there was no obvious way forward to invite them to participate.

#### **4.6.2 *The interviews***

All four face to face interviews were completed remotely. Three interviews were completed using MS Teams, two with audio and video and one with audio only. One interview was completed by phone. All participants gave their informed written consent for the interview to be audio recorded.

Interviews ranged from around 40 minutes in length to well over 2 hours. One interview came to an abrupt halt due to poor internet connectivity but was recommenced within a few minutes and continued to its natural close thereafter. One interview was momentarily interrupted by someone coming to speak to the participant. No participant showed signs of being unduly distressed by the content or process of the interviews.

No participant got in touch with the research team after the interview except to claim the £20 voucher offered as partial compensation for their time. One participant did not reply in relation to the offer of a voucher; the other three accepted and confirmed its receipt.

I transcribed the interviews straight away where possible and within 48 hours of the recording in all cases.

#### **4.6.3 *First level categories***

Although in depth analysis of each interview transcript was planned to commence at least 6 weeks after I had transcribed the interview, in practice, due to the difficulties recruiting, there was a delay of several months between transcription and analysis. Although it would have been preferable for recruitment to have proceeded more swiftly,



the delay optimised the extent to which I could return to the material after a break and therefore be as unbiased as possible in the context of having conducted and transcribed the interviews.

Small differences emerged between the two sets of independent coding (mine and my supervisor's) where we had used terms or phrases with similar meaning but different wording. In relation to an excerpt about emptying a parent's beer cans down the sink at a very young age, for example, I coded this as 'taking charge/ acting as though the parent' whilst Pamela Taylor coded this as 'caretaker role – for mother and others'. In another example, I coded 'not giving up' and Pamela Taylor coded 'keeping going'. We had used the same pieces of data, but picked out different words to capture the category. Pamela Taylor coded 'physical privation/poor' and I coded more specifically 'feeling hungry'. Other discrepancies were even more minor, for example I had coded 'resenting parent' and Pamela Taylor coded 'resentful'. Other categories we had labelled identically. By accepting that some codes were so similar as to be essentially the same – such as 'resenting parent' and 'resentful', I calculated that overall, we had over 95% agreement across the three interviews which we both coded. Following discussion, we were satisfied that the differences between our coding, where they existed, were so minor that it would be acceptable for me alone to code subsequent interviews, which in the event was only one further interview.

Once I had completed coding for all 4 interviews I had over 150 first order categories (see Appendix N), and new categories were still emerging in the fourth interview, so data were not saturated. The lack of data saturation did not affect the level of analysis which could be performed but does impact on the weight that can be placed on the core concern, its resolution and the model, each of which are described in the next few sections. Appendix N provides all the first order categories and the supporting quotation(s). These first order categories are then grouped within the higher order themes which emerged. I will now show how first order categories were identified and then grouped into higher order categories. A first order category of participant 'resilience' was coded from several quotations which seemed to point to it being important. These included one participant who said

*'I'm very resilient and I don't even know how that happened because I didn't have any support'*

and another who said

*'I also think I can handle change erm quite easily now, like nothing can shock me I feel and actually that is a really, really important skill. Yeah, having the resilience to, you know, I appreciate what I have now, but if things were taken away from me or anything changed then I feel like I'd be able to cope with like that'*

whilst a third participant said

*'you know like we've not had the best cards handed to us growing up and we had to be a mixture of resourceful and resilient to push through'.*

These quotations are quite long and some of the text captured generated other first order categories too, such as the quotation

*'we had to be a mixture of resourceful and resilient to push through'*

from which I also coded 'being resourceful'.

During the initial coding of the interviews, I began to see some categories which seemed to involve similar themes, such as those mentioned above of 'resilience' and 'being resourceful', which both seemed to be participant strengths. Categories were tested out to see which ones fitted together into higher order categories. Constant comparative analysis enabled testing and retesting of various higher order categories, examining them against the full range of first order categories and the supporting data, focussing in on the detail of the transcripts at times and at other moments stepping back to reorientate myself to the wider picture. This was all whilst being mindful not to impose my own expectations of what might be found in the data into the categories.

Memos were particularly useful during this stage of analysis. They felt unpressured, were just for me, and I didn't feel that I had to get them 'right' in the same way I did when looking for categories. Glaser (1998) encourages researchers to have confidence in oneself and to know that any 'reasonably bright' individual can adequately conduct grounded theory but holding on to that was a challenge at times. Memos felt particularly helpful to capture my thoughts during the constant comparative analysis and were especially containing when I wanted to document why I had changed my understanding about which first order categories belonged together or why I had amended the description of a higher order category. In the next section I will detail the model of understanding of the offspring experience, which emerged from the higher order categories, and which included the offspring core concern and resolution.

#### ***4.6.4 The core concern of the children and description of the model of understanding***

The model of understanding of offspring experience which emerged from the participant interviews is shown in figure 4.1. The model includes eight boxes, each of which contains one of the higher order categories which emerged from the data. The two boxes which have a bolder outline include firstly, the core concern, on the left, which is 'chaos and confusion' and in the box to the right, the resolution of this, which was through 'stability, security and autonomy'. The core concern and resolution will be described in detail below, together with an explanation of how the other higher order categories relate to the participants' journey from experiencing the core concern to resolving this. The arrows on the model indicate the relationship between the various higher order categories. Arrows with just one point indicate that the direction of travel or influence was unidirectional, or on balance primarily unidirectional, such as the participants' journey from their experience of the core concern of 'chaos and confusion' to resolution which was found in 'stability, security and autonomy'. This can be contrasted with the bidirectional arrows between the core concern of 'chaos and confusion' and each of the participants' 'difficult emotions' and 'memory problems', where the arrows indicate that

these both contributed to the core concern but were also generated by it. The width of the arrows do not hold any meaning.

The core concern – the overarching category that best encompassed and explained the data to date - was the chaos and confusion that the participants experienced, especially in earlier life. The word ‘weird’ recurred in the participant narratives and a sense of the situation being ‘mad’ and ‘crazy’. Much of the chaos and confusion stemmed directly from the parental psychiatric disorder. Participants spoke of being part of their parent’s delusions, of witnessing their parent struggling with psychotic symptoms and of experiencing their parent being intoxicated. Parent-child contact was described as ‘hard and confusing’, and the parent was at times unrecognisable to the child. Parent-child role reversal created self-explanatory challenges and tensions which were exacerbated by the child’s lack of control and choice. Lost in the chaos were the child’s own needs, including diagnosable conditions, which left offspring struggling without the right support.

There was a sense of resolution of this chaos with a move towards an experience of stability, security and autonomy, mainly in adulthood, with offspring having developed their own aspirations, identified and maintained their own boundaries, and found clarity in their identity. Some stability was afforded by the parent being in secure care and any associated recovery brought with it a little more ‘normality’ in the parent-child contact. Acceptance, and maintained or renewed affection for the parent went with the sense of security. The arrow between core concern and resolution is unidirectional as there was minimal sense of backward movement in this small group. Offspring resolution strategies are shown feeding into the process, as are the offspring’s inherent strengths which seemed to form a key factor in promoting resolution, and the barriers encountered. The qualities of memories and feelings are shown underneath the core concern, with the bidirectional arrows indicating the complex relationship between the presence of the core concern and the emotions and memories generated. The offspring experience of professionals did feature but was not central to either the core concern or resolution of it, so sits somewhat apart, present, but not critical to the offspring experience.

Personal strengths were evident in all the participants and appeared important in enabling the resolution of the core concern. Participants articulated and demonstrated resilience, resourcefulness and empathy. Despite the challenges in the parental relationship offspring reported that they felt loved and bonded with others, whether a sibling, grandparent(s), partner or their own child.

Offspring strengths enabled their engagement in strategies facilitating resolution, such as talking, sharing and developing a wider perspective on their situation. This 'wider perspective' was in contrast to their narrow childhood experience of the parent's illness being their then 'normal'. Internal strategies which helped resolution included 'keeping going', acceptance of their situation and not blaming oneself. Alongside and interspersed with these strategies were also times when offspring felt they needed to step away from their parent and block things out.

Although all participants in this small group had found resolution, they described many 'barriers' to this. Barriers included the non-linear nature of their parent's recovery; the ups and downs in their parent's health, and associated fluctuations in offspring hope all took their toll. Another barrier was offspring sense of lack of control over contact with their unwell parent. Factors in this included either feeling pressured into contact with the parent, or else being forcibly separated from the parent, whether by the authorities - graphically described as 'being dragged away' - or through the side effects of their parent's psychotropic medication. Family processes also presented barriers to resolution at times, such as when different and sometimes confusing narratives were at play, including the well parent 'badmouthing' the unwell parent or denying the very existence of mental illness. Some barriers were very practical including changes in living arrangements, being hungry and isolated. Others were less tangible, but as real, including a sense that others were unable to truly understand and empathise with them, feeling unheard, or their awareness of the genetic component to their parent's illness, and in turn their own vulnerability.

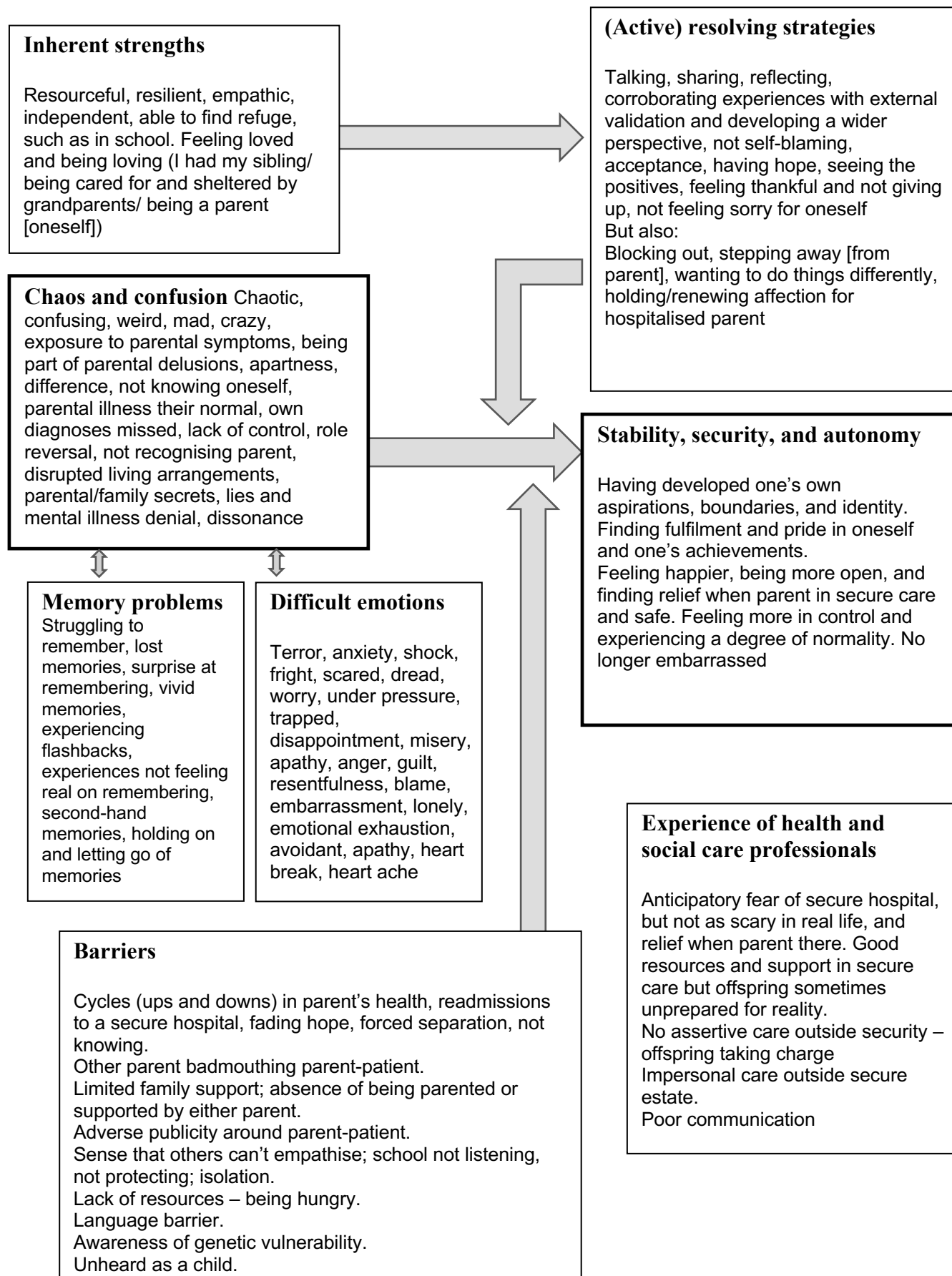
Participants also described many 'difficult emotions', which had at times dominated their journey. Some of these were directed at the unwell parent, with feelings of blame,

resentment and anger being articulated. They described anxiety around their parent's safety as well as their own safety and the safety of loved ones in relation to their parent's psychiatric disorder. Duress could become such that participants described themselves feeling emotionally exhausted, apathetic, or weak. There was also criticism of the well parent at times, in terms of their emotional availability and/or understanding, and in relation to some key decisions made about the offspring's lives. However, overall, the description was of parents and families doing their best with the resources available.

Memories, and the process of remembering or not remembering, also featured strongly in the participant's accounts and were grouped into the category of 'memory problems'. This was likely to have been, in part, because they were being asked to remember, in order to respond to the question posed, but the discourse which emerged included reference both to difficulties remembering and of surprisingly vivid memories. The traumatic nature of experiences was evident in the way some memories presented, either as flashbacks or with a sense of unreality.

Healthcare professionals did feature in the participants' narrative but had not been central to the resolution of their core concern. Healthcare professionals, who are included in the category of 'experience of health and social care professionals' had often been ineffective, whether by not knowing the parent, or not being sufficiently caring or controlling in terms of reticence to force medication and/or to detain the parent under the Mental Health Act. There was some reflection as to how professionals outside of healthcare, such as social services should have been more present in their lives when they were children – although others recalled intrusive and traumatic interventions by the authorities. There was one participant account of schools not acting when disclosures were made, but more usually school was, in various ways, a place of refuge, whether through simply belonging to the child rather than the parent, or through teachers providing emotional support and opportunity to talk or referring on to counselling.

**Figure 4.1. The model showing the offspring core concern and resolution**



#### **4.7 Preliminary testing of the model in the semi structured interview responses**

This model offers a framework for understanding the experience of adult offspring of parent-patients who are, or who have been, detained in a secure hospital. In the absence of a research literature relating directly to the experience of these offspring, the participant responses to the semi structured interview were used to provide some preliminary testing of the model.

The presence and importance of the chaos and confusion in offspring life and the plausibility of this as the core concern was confirmed in the participant responses to the semi-structured interview. Chaos was captured in various scenes, for example, when asked how they had found out about the parent having been in prison, one participant recalled that they had received a letter from the parent and was

*‘trying to read it and ... my dad snatched it out of my hand and he burnt it in front of me ... I said, I saw it said prison, it said prison, and...I was pretty young, I was probably like 8 or 9, maybe younger. My dad eventually said yes, she’s been in prison’.*

For another participant it was only in the semi structured section that they recalled having been removed from the family home and placed in foster care for 6 to 12 months. For two participants the confusion from different narratives within the family really came through in the structured responses. For example, being told on the one hand that their parent was mentally ill and in a secure hospital whilst hearing from the well parent that

*‘there’s no mental health problems, it’s just her being attention seeking’.*

For another participant the challenge was trying to reconcile the parent’s recollection of themselves having been neglected in childhood compared to the grandparents’ account of the parent having been a favourite and having had everything he needed.

‘Weird’ was used by several participants when searching to describe their experience in response to direct questions as well as having had prominence in the open section. It was



used to respond to a question about the first contact with the parent-patient after their secure hospital admission

*'when I first saw him it was weird because I think at the time I was still angry at him'.*

Another participant used it in response to enquiries around their relationship with the other, well parent,

*it's very weird because ... you don't talk about your feelings'.*

That the participants had a different 'normal' to other children also came through in responses to the more structured questions. One participant, when asked about how she found out about her parent being in a secure hospital, reflected

*'I don't know, no it doesn't stick in my memory how I found out. It just seems, I know this is going to sound crazy, but it's been like the norm.'*

The emotional experiences of participants and the relationship between these and their experience of the chaos and confusion was also evident in the semi-structured interview. One participant said

*'Yeah, I think I would have put a lot of blame on my dad because I didn't understand the illness. Like I was so angry with him. Like, really angry.'*

In terms of evidence from the semi structured responses for the resolution of the chaos and confusion, this was captured in several places. When asked about their current contact with the unwell parent, the tentative moments of relative normality came through

*he's actually starting to have conversations where he's able to give me advice whereas it had never been like that for years so yeah its quite nice.'*

Another such quotation was

*'he started getting better and I realised how much better he actually was - I could enjoy the time with him'.*

The dissipation of feelings of embarrassment were also articulated in response to the questions around stigma, with one participant saying

*'I used to feel quite embarrassed about it but, so like I personally don't have an issue with things like this anymore'.*

Perhaps relating to the barriers which participants experienced, an absence of physical affection in childhood was also noted by participants in the semi-structured responses. One participant thought back saying

*'that actually sounds a lot sadder than it was, because at the time I didn't feel like I needed it'.*

Another participant said

*'me and my family, my mother and father we never cuddled or hugged or anything nothing like that, it was really odd'.*

The experience of health care professionals or social workers being detached in the model appeared consistent with detail elicited in the semi structured interview.

Reflection on missed diagnoses in themselves and in wider family members was captured in the grounded theory analysis but experience of healthcare professionals had not come through as *central* to the offspring experience. Important details about the offspring experience, such as having been repeatedly operated on as a child, or having been prescribed psychotropic medication, did not emerge until the semi-structured section and direct questions. This reiterated the experience of healthcare professionals not having been central to their experience.

## 4.8 Stigma

### 4.8.1 Introduction

In the qualitative work described in this chapter, the word stigma was not used by any of the participants in their response to the initial open question about how they had experienced having a parent in a secure hospital. 'Stigma' also does not feature verbatim in the core concern or the model of resolution, which were informed by the words used by participants and what they actually said in response to the open question.

Nevertheless, stigma can be detected in the core concern in categories such as 'embarrassment', 'apartness', 'difference' and 'mental illness denial', this latter category referring to within the participant's family. Stigma was therefore evident in participant's answers to the open question, if not named explicitly. Following each participant's response to the open question, as part of the structured interview, each participant was asked directly about stigma and participant responses to this direct question are incorporated into the discussion below. I will briefly outline the different types of stigma, and then bring in evidence substantiating this being present in the interview transcripts. Because the answers to the structured questions were not part of the grounded theory analysis, some of the quotations included below do not feature in the first order coding which is captured in Appendix N.

Stigma was first definitively described by Goffman (1963) as '*an attribute that is deeply discrediting*', which reduces someone '*from a whole and usual person to a tainted, discounted one*' (p. 3). Stigma has been discussed in relation to a wide range of characteristics including mental disorder (for example, Ahmedani, 2011) and, separately, offending behaviour, especially imprisonment (for example, Moore, Stuewig and Tangney, 2016). For patients in a secure hospital there are therefore at least these two aspects of their lives in relation to which they may experience stigma. Patients may also experience stigma in relation to other characteristics such as gender or ethnicity although it is beyond the scope of this discussion point to explore these in detail. Goffman (1963) recognised that stigma also extended beyond the directly stigmatised person to those 'associated' with them, often referred to as 'courtesy stigma'. Offspring

are inextricably associated with the parent, especially in relation to mental disorder, for which biologically related offspring carry the risk of genetic intergenerational transmission as well as any associated social and environmental risks.

The literature around stigma has developed considerably since Goffman's seminal work and researchers have sought to tailor definitions, operational models, and research discussion to the specific stigmatised characteristics, including mental disorder (Link et al 2004; Corrigan and Kleinlein 2005; Rüsch, Angermeyer and Corrigan, 2005). The proliferation of literature has maybe made the pursuit of an agreed way of examining stigma more challenging. However, literature supports the view that stigma can be internalised and operates within the person, as well as between people (whether direct stigmatisation, or in the stigmatised individual's fear or anticipation of the other's response), within institutions (such as education, health and police) and at a wider societal level (for example through the media). As Dobener et al., (2022) notes, courtesy or associative stigma has not been thoroughly appraised in the same way that direct stigma has, but I will relate the evidence from these interviews with the offspring of secure hospital patients to the broad operational levels of stigma, to include:

- within the person (internalised or self-stigma)
- between people (for example direct stigma/experienced stigma, or perceived stigma, or anticipated stigma)
- within families
- within institutions, for example education, or the legal system
- at a wider cultural or societal level such as stigma in the media.

#### *4.8.2 Self-stigmatisation or internalised stigma*

Self-stigmatisation or the internalisation of stigma in the context of courtesy stigma has been described as including feelings of embarrassment, shame, and a need by offspring to hide their parent's illness (Dobener et al., 2022). There were several examples of participants describing these sorts of feelings, with one participant in my study reflecting

*‘to be honest I used to hide it from everybody, I was so embarrassed as a kid and I ... literally ... wouldn’t bring people over if he was ill’.*

There were multiple references to participants feeling embarrassed both generally about their situation but also specifically about being seen with the unwell parent. One participant said

*‘I still felt really embarrassed initially like walking around town with her’*

whilst another recalled

*‘I think dreading bumping into him when I was out with my school friends and things in case he was embarrassing because he was on drugs’.*

In the same broad category of internalising stigma, Dobener et al., (2022) also included a number of specific subcategories, first the offspring’s sense of being ‘different’. In my qualitative research one participant reflected

*‘as a teenager, like I don’t know, it always felt like our relationship was very different to our friends’.*

Secondly, Dobener et al., (2022) reported offspring feeling different in terms of their having to mature more quickly. Again, this was evidenced in my qualitative research with one participant saying

*‘I had to grow up a lot quicker than I should have done’.*

Thirdly, Dobener et al., (2022) described internalised stigma as a ‘self-reflexive sensitivity’ to any experiences which may indicate that the offspring felt s/he was becoming psychiatrically unwell, probably as awareness of their own genetic vulnerability, and leaving them feeling ‘contaminated’. There are two statements

relevant to this in the participant narratives from my research, with one participant saying

*'it's on our heads. We know that we're like genetically more prone'*

but also describing the self-reflexive sensitivity

*'sometimes I think I might be overthinking it and I think oh maybe I'm slightly bipolar or maybe I'm this'.*

However, another participant had actually been diagnosed with a mental disorder and prescribed medication in the past

*'I was on sertraline for a few years but I'm not on that anymore'.*

It is possibly a tricky balance to strike between being overly sensitive to any fluctuations in one's own mental state on one hand, and lacking insight if a mental disorder were developing on the other hand.

#### *4.8.3 Interpersonal stigma both experienced and anticipatory*

There was evidence of direct or experienced stigma in the participant narratives. For one participant they described how they had been present when someone had commented negatively about their mother's physical appearance, which was at least indirectly related to her mental health

*'someone in the restaurant would make a comment about her weight or the way she was eating, not so much about her mental health, but more so... I guess, the results of it'.*

There were many examples of anticipatory stigma, where participants had been afraid of being stigmatised by others. One participant, when asked directly about whether she had experienced stigma related to this immediately, saying

*'oh gosh yeah... massively, yeah'.*

This participant then went on to add detail of anticipatory stigma, recalling

*'going over to like friends' houses and making new friends in comprehensive school and going over and then they're like who's your mum, who's your dad ... and I'd automatically I'd be like, I live with my grandparents and I'd give my grandparents' names, like sort of hiding'.*

Another participant in my research who felt able to disclose her parent's whereabouts to peers nonetheless had some discomfort associated with this, saying

*'when people say casually you might get asked by your teachers 'oh what does your mum do?' You know, that's like a question what do they do? 'Oh well my mum's just in hospital'. Like, when they ask, 'oh she doesn't work?' ...There's always those assumptions about like what parents are supposed to be doing'.*

There were several other examples of anticipatory stigma among participants in my research which involved worry that others would not understand. One participant reflected that

*'most people can't really empathise with it... people can't relate to it'*

and therefore expected that

*'people are going to be awkward and uncomfortable'*

if she brought the subject up. The same participant said,

*'when people haven't had a similar experience, I feel like they wouldn't be able to help with some concerns or issues that I might be feeling'.*

Another participant reflected the challenges of trying to work out how to describe her situation, as well as worry that it wouldn't be understood, which maybe also taps into other areas of stigma, as healthcare professionals/teachers/other adults had not helped her with her mental health literacy

*'I would hide it and I would never tell people, the only time I might say to my friends oh my dad isn't very well, but how do you explain schizophrenia to a 12 year old? You know, they don't know what that is, I don't even think I knew what that was at that time.'*

Reupert et al., (2021) discuss low mental health literacy as a consequence of stigma and how this results in silence within families.

In an example of direct stigma, one participant spoke of how other adults avoided the issues clearly at hand. She recalled

*'other people definitely could have helped more, erm like my friend's parents as well probably. I used to run to them and get upset like if my mother and father were arguing and the police were called. I'd go over there and I'd be upset at their house but then they would just send me home so like it was just like no one ... wants to get involved. No one wants to, I don't know, people ... think it's better not to say anything'.*

#### 4.8.4 Stigma within the family

There was evidence in my qualitative research of the parental psychiatric disorder being stigmatised within the participant's family. The other parent was at times the source of this, with participants all too aware of this

*'I didn't tell my dad that I'd told anyone else [about the mother's mental illness] or that I went to counselling because I felt like at the time my dad wouldn't understand'.*



There was also an example of the unwell parent's offending behaviour being stigmatised by the well parent, by them keeping it a secret from the offspring, and telling them that the parent was away studying rather than disclosing that the parent was in prison. Another participant did not find out that their parent had been in prison until the parent had been transferred to hospital.

Stigmatising attitudes were also described from the parent-patient's perspective – either towards him or herself or towards other patients on the unit. One participant in my qualitative work said that

*'my mum [is] the main perpetrator against herself in a very strange way' and 'she calls other people on her ward crazy'.*

#### *4.8.5 Institutional stigma*

There was evidence of institutional stigma in both education and health settings within the participant narratives from my research, and evidence of this from within the police and legal system (albeit the latter in the USA) in the wider research literature (Dobener et al., 2022). In education, although all participants in my research valued school, for various reasons, whether as a place of relative safety, as a break from their unwell parent or as the source of a trusted adult, there was one very striking example of school completely failing to acknowledge, let alone act on, disclosures around the participant's home life. This may reflect institutional stigma. The participant described how the teacher had tasked the children to write a letter and the participant explained

*'in the letter I actually wrote about everything that was going on at home, like that I was afraid to go home, and I remember writing about my dad [the unwell parent]. And I put it in the box, and I was hoping someone would read it but no one ever did ... and I never did anything after that.'*

Regarding healthcare professionals, there was evidence of participants sensing that healthcare professionals were perhaps not as attuned to the parent as they could have been. One participant reflected on staff and their interaction with her parent

*'they don't know him .... It's okay, but it's not personal'*

whilst another participant explained that staff hadn't updated him on his parent

*'we weren't told the changes that had happened.... It would have been nice to know what was going on'.*

Whilst these problems in the healthcare provision can be framed in a number of ways (for example, incompetent or overworked staff), Dobener et al., (2022) described inadequate service provision as part of structural discrimination from within the mental healthcare system. There are also likely to be genuine concerns on the part of staff about risk of breaching confidentiality when talking about a patient, even to family, including the Next of Kin and/or Nearest Relative. In most cases this can be managed for everyone's benefit, but the process needs skill, sensitivity, and time.

#### *4.8.6 Cultural or societal stigma*

Culture was most explicitly spoken about by participants who had a parent with a different cultural background. One reflected of their well parent's cultural background

*'mental illness is ... not seen as a thing, it's just someone being weak .. or.. attention seeking'.*

Societal denial of mental illness of another kind had affected another participant who, after observing that as a child, friends' parents were aware of some of the chaos and problems at home but did not act on this, reflected

*‘where I lived it was a working-class area, pretty much majority was council estate and back then it was normal to grow up in a bit of chaoticness’.*

One participant also spoke of their parent’s offending behaviour having drawn media attention and how living in a small place this had resulted in awareness beyond the family home of what had happened, saying that

*‘everybody would know’.*

This exposure of one’s family background within the local community was reported in a matter of fact manner but this participant was also the one who most openly and readily identified having experienced stigma when asked directly, despite it not having featured in the participant’s response to the open question.

#### **4.8.7 Conclusions**

It is clear then that there was evidence in each of the participants’ accounts that stigma had permeated their lives at many different levels, even for participants who in other ways had been relatively sheltered from some aspects of their parent having been in a secure hospital, for example by living with their well functioning grandparents. It is interesting that the participants did not spontaneously report or describe stigma in response to the open first question in the interview and this may reflect how deeply ingrained the stigma is. Stigma will be discussed further later in the thesis.

### **4.9 Discussion**

#### **4.9.1 Introduction**

The core concern of these offspring who had had a parent detained in a secure psychiatric hospital, was one of ‘chaos and confusion’, but this was something that they had all resolved by the time of their interview in adulthood. This raises three key

discussion points. First, does the research literature give any indication as to how representative the offspring experience in this study may be – for example as that of offspring of parents with serious mental disorders, who do not necessarily have the risk behaviours or separation(s)? Secondly, given that the participants in this study had all found resolution and were doing well, what, if any, need is there for intervention by healthcare professionals? Thirdly, if there is a need, what are the barriers to the staff who are looking after the patient-parent engaging with the offspring? I will address each of these points in turn before addressing the limitations and strengths of the research and indicating suggested future directions.

#### ***4.9.2 Does the research literature give any indication as to how representative the offspring experience in this study may be, of for example, offspring of parents with serious psychiatric disorders?***

A key driving factor for pursuing this thesis was the paucity of research interest in the offspring of patients detained in secure settings. Research evidence was so scant that when testing the model which emerged from the research data in my qualitative work, the primary source of material was evidence from the participants themselves, from a more structured interview. However, since my project has been underway, a qualitative study in which the researcher interviewed young adult carers who have a parent with a severe and enduring mental illness has been published (Blake-Holmes, 2020). Whilst neither the populations nor the theoretical approaches employed are identical, it is a useful context to examine my research findings and model, given that both papers include narrative from young adults who have experienced severe and enduring parental mental disorder. The Blake-Holmes (2020) research was looking specifically at young carers' transition to adulthood, whilst my research did not mandate that participants identified as young carers and was seeking to understand the overall experience of having a parent with a mental disorder, rather than focussing on one role or transition. However, of the five themes which Blake-Holmes (2020) identified, two very much reflected content from the model from my research. These were 'exercising agency' and 'maintaining boundaries'.

In the theme of exercising agency, Blake Holmes (2020) described how this captured the impact of the participants' parental mental disorder on their sense of agency and ability to engage with the world. Notably, given that chaos and confusion was the core concern in my research, one participant in Blake-Holmes (2020) project spoke of just wanting to be *'settled'* with an *'ordinary life'* and *'no chaos, or as little chaos as possible.'* One participant is quoted as saying *'it's like having a child you never gave birth to'*, which resonates strongly with the role reversal category that was part of the core concern.

The theme of creating and maintaining boundaries, included psychological and physical boundaries, and related to the participants' strategies to make sense of the impact of the parental mental disorder. Blake-Holmes (2020) describes the participants as being somewhere on a spectrum from *'enmeshed'* to *'self-determining and resilient'*. This resonated with the movement of participants in my study from a position of chaos and confusion to stability, security, and autonomy.

Participants in my study had little backward movement towards chaos and confusion and the context provided by the Blake-Holmes (2020) study led me to wonder whether the parental secure hospital admission was a catalyst, or even a facilitating factor, in enabling offspring to progress towards resolution, even if the input of healthcare professionals was not directly important in the offspring accounts. For example, the sense of *'relentless responsibility'* that 6 participants in the Blake-Holmes (2020) work described was interrupted for the participants in my research by the secure hospital admission(s) allowing a sense of relief and providing a mental break. One participant in my research reflected

*'I felt relieved that it was now my own choice to go and see him and then walk away'.*

Another said,

*'it was a big relief'* with a third saying *'I sort of had that peace of mind'.*

Whilst participants in my research were able to talk about the relief of the secure hospital admission and of knowing where the parent was and of their safety, many participants in Blake-Holmes's (2020) research spoke of practical and emotional

challenges of making space for themselves and their caring responsibilities. Some reflected on the futility of their situation, particularly for participants who were still living with their parent, with one quoted as saying *'this is my life and I can't change it.'* Another participant was quoted as saying of the parent *'she's not going to go anywhere. I'm always going to feel responsible, and much as say I'm having a break, I'm never going to have a break mentally'.*

For some participants in the Blake-Holmes (2020) study, being a carer for their parent had reduced their perception of their choices in life and perhaps their scope to pursue resolution. One participant explained that she would have gone to university if it wasn't for her caring responsibilities, whilst another had gone to university but then left to care for her parent. A further participant would like to be able to work day rather than night shifts, but caring for her parent had precluded this. By contrast, participants in my study had not felt hindered in pursuing educational goals by caring responsibilities for the psychiatrically unwell parent, although one had taken time out of university to care for the other parent when she was terminally ill. One participant in my study spoke of how important it was to them to have been able to find what they were good at despite not having had the support which they would have liked:

*'When you're younger and like you're facing all these adversities or whatever and you don't really know what you're good at because you haven't had the support or the parenting that you probably should have had so you don't really know where you fit so it was nice so I've found the job that I'm good at'.*

This satisfaction in career achievements didn't appear to have featured in the Blake-Holmes' (2020) participants' narratives.

In conclusion then, the experiences of the participants in my research appeared very comparable in some ways to the experience of a group of young adult carers who had a parent with a severe and enduring mental illness. However, my participants had all achieved resolution and were no longer in a chaotic scenario, whilst the young adult carers whose parents were in the community spoke of an unrelenting situation and of

not having had the personal physical or emotional space to pursue (or in some cases even to define) their education or employment goals, or to develop intimate relationships.

Given the small number of participants who took part in my research it may be that only people who had attained resolution felt comfortable to take part. However, within the larger project by Blake-Holmes (2020) there was no sub-group reported who had subjectively had a more favourable experience. Furthermore, a qualitative research project with adult offspring of parents who had been in prison, which was actively recruiting offspring who were enrolled at university, and therefore well-functioning, still had some challenges in recruiting, and only 5 of 12 potential participants who definitely knew about the study actually took part (Zhang and Flynn, 2020). As identified throughout the literature reviewing, there is a general paucity of research which hears first hand from the offspring in situations relevant to my population of interest, and that which is available is often asking them about their retrospective accounts of their earlier life rather than where they are contemporaneously to the research (Smith and Young, 2017). This makes it impossible to assess whether those participants had attained resolution of previous core concerns relating to their experience of their parent being, for example, in prison. Stigma, which will be discussed in chapter 5, may have been a barrier to offspring taking part in my research prior to having attained resolution. If the chaos and confusion is ongoing, offspring may find it challenging to participate on practical grounds as well as perhaps holding fear of 'contaminating' the researcher (Dobener et al., 2022). The evidence is therefore very limited in trying to understand whether only participants who had resolved their concerns were willing to talk about them in my research. It seems likely though that participating, or not, is a decision contributed to by a more complex mix of factors than simply whether the participant is functioning well, or not, by very crude social standards such as whether they are in education or employment.

#### ***4.9.3 Is there a need for intervention from healthcare professionals, for the offspring?***

This question arises because the participants in this research, despite the evidence of their anticipated needs in the earlier literature reviewing, not only resolved their sense of chaos and confusion, but were also doing well in their various pursuits, whether personal or professional. This does not, however, mean that they did not need help at various key points in their life in relation to their parent's secure hospitalisation, nor that with additional help, they couldn't have resolved the core concern earlier. Also, if, as is suspected to be the case, other potential participants did not take part in the research because they had not attained resolution, meaning the participants I spoke to were not representative of the wider group of such offspring, then there would be a clear argument for the need for additional resources to support this group. It seems therefore that there is likely to be a strong argument for ensuring resources for this group but given the good outcomes for the participants in my research, I will explore this more thoroughly.

As indicated above, the participant interviews provided evidence that the participants had been able to make sense of their situation and attain resolution without direct support from healthcare professionals. The participants making sense of their situation is captured in the model by the resolution of the core concern through the category of 'stability, security and autonomy'. The remoteness of the healthcare professionals to this process is reflected in the participants' experience of them as being in the 'experience of health and social care professionals' category, which sits apart from the other categories in the model, not joined to the other categories by any arrow(s). There were two participant quotations which particularly seemed to suggest that participants can resolve things without specific intervention, which included, when asked about whether they would have given a different response to the open question at a younger age, one participant who replied:

*'Yeah, I think I would have put a lot of blame on my dad because I didn't understand the illness. Like I was so angry with him. Like, really angry. At one point I remember just screaming at him why can't you be normal?'*



And another who replied

*'I think now I'm much more, like understanding and reflecting, and I'm a bit like, well I try and see things from a balanced point of view'.*

Given how much these offspring had achieved with apparently little input from professionals, is there a robust argument for providing resources to this group?

Before dismissing need in this group, it is important to note that even these offspring, who had attained resolution, expressed a view that they probably had unmet needs when younger, although there was also some retrospective reflection that they may have been hard to engage:

*'I feel like part of me at the time, I don't think I feel like I needed to or wanted to [talk to an adult], even though looking back now I think part of me feels that that would have been really helpful'.*

Furthermore, even having attained resolution, one participant had not completely dismissed the possibility of ongoing need for therapeutic input

*'Sometimes I think like would I benefit from going to therapy to talk but I don't think I'd benefit from it because it would just like bring up everything and then I'm like what's the point?'*

Although one to one talking therapy may be helpful for some offspring, support for this group could include less resource intensive activities such as good quality psychoeducation provided in a way which the offspring can understand. The challenges faced by offspring of parents with a psychiatric disorder to simply find out about their parent's condition came through strongly in Yamamoto and Keogh's, (2018) systematic review of qualitative work.

It is also important to consider the wider perspective and acknowledge that there is evidence that the participants in this study, who had had such good outcomes, may not be representative of all offspring experience. One reason being that given that I was exclusively interviewing adult aged offspring, they were, by being older (the age range of participants was 26 to 31 years) more likely to have attained resolution than younger offspring, and especially compared to offspring whose parent had only recently been admitted to a secure hospital. It is also plausible that only people who had attained resolution were willing to be interviewed. One participant reflected that

*'I don't mind talking about it, sometimes it's nice to recognise how far I've come and it's quite nice, it's a nice ending, not like a bad ending, so I don't mind talking about it. It's not like anything horrendous happened with dad like, so he's still there isn't he, he's in the best place he can be so just happy for that'.*

It is also possible that some potential participants who had not attained resolution were among those considered too vulnerable by either their parent or healthcare professionals to even get as far as being made aware of the project. Given these considerations, it seems prudent, on balance, to anticipate that not all offspring will have attained resolution.

When considering whether resources should be allocated to this population, it is worth viewing it from a societal and even global perspective. The World Health Organisation (2013) and many scientific and public policy reports recognise that offspring of parent(s) with a psychiatric disorder, warrant special consideration, and those who are identified as ultra-high risk should receive preventative intervention (Adderley et al 2020; Devaney et al., 2020; Weissman et al., 2016). Legislation and policy have required support for the wider family of parents with psychiatric disorder(s) for many years, and for children more specifically in the Children, Schools and Families Act, 2010, and the Care Act, 2014. Despite this legislation, the reality has fallen short at times with Ofsted (2013) reporting inadequacy in whether adult mental health services even record the presence of patient's children, and, if applicable, whether the child's and wider family's needs are being met (Dunn, Startup and Cartwright-Hatton, 2021). Dunn, Startup and Cartwright-

Hatton, (2021) have found ongoing inadequacies in this basic preliminary work to enable professionals to know that children exist, let alone understand that they have a voice. Only if they do this are healthcare professionals likely to be aware of the offspring's internal struggles, for example with the tension between being the child, but often acting as the parent within the parent-child relationship, as captured in the core concern.

Family focussed practice (FFP) is very pertinent here and refers to an approach in which the whole family's needs are considered rather than focussing on one individual, whether that be a parent, child, or another relative (Foster et al., 2016). There is still no agreed definition of Family focussed Practice (Lagdon et al., 2021), but it generally comprises a range of elements including the direct treatment of the parental mental disorder, but also psychoeducation for the family, focus on parenting behaviours, family communication; family support and functioning, and, explicitly, child risk and resilience (Foster et al., 2016). This may present challenges given the organisation of services, with separate services for adults as opposed to children, and communication issues perhaps limiting joint working for effective service provision to the whole family (Stanley, 2003).

A systematic review in 2014 (Bee et al., 2014), which examined the literature for evidence on the clinical effectiveness, cost-effectiveness and acceptability of community-based interventions aimed at improving or maintaining quality of life in children of parents with serious psychiatric disorder, drew the conclusion that there was insufficient relevant evidence. Since that time, further publications - Grant & Reupert, 2016; Goodyear et al., 2015; Shah-Anwar, Gumley, & Hunter, 2019 - have supported the need for interventions for both parents and children, as cited by Devaney et al., (2020). A 2021 systematic review of literature on Family Focussed Practice included 40 papers, of which 30 reported on interventions which involved parents and children, and a further 6 papers in which interventions had been for the offspring alone (Lagdon et al., 2021). Of the 40 included papers, most (29) involved some sort of family support, 22 addressed to some extent communication within the family and 21 addressed child risk and resilience (Lagdon et al., 2021). Child outcomes reported included 'improvement in child behavioural and emotional functioning' (6 studies), 'reduction in children's stress' (7

studies) and ‘better understanding of parental issues’ (7 studies), which suggests that there is benefit for offspring from Family Focussed Practice (Lagdon et al., 2021).

Lagdon et al. (2021) note that there was little consideration in the literature they found of families’ priorities or experiences. Whilst my qualitative research did not elicit participant accounts of having had emotional or behavioural problems in childhood, difficulties understanding the parental psychiatric disorder were universal, and developing understanding and a wider perspective was an important part of attaining resolution, as indicated in the participant quotations from the beginning of this discussion point. There is therefore potentially scope for similar intervention to help offspring of patients in secure settings attain resolution earlier.

Family focussed practice can also help reduce the risk of intergenerational transmission of psychiatric disorder(s). Whilst some of this risk is accounted for by heritability, environmental factors are also present (see chapter 2) and offer opportunity for intervention to improve outcomes (Garber et al, 2009; Eley et al., 2015). This risk was something which the participants spoke about in interview with one reflecting

*‘it’s on our heads. We know that we’re like genetically more prone’* but also that *‘a huge part of it is environmental and we have a pretty, a very, very different upbringing’*.

Siegenthaler, Munder and Egger’s (2012) meta-analysis indicated that intervention could reduce the risk of offspring developing the *same* disorder as their parent by 40%. The scope for intervention to provide intergenerational benefits has been replicated in subsequent work (Grant and Reupert, 2016, Tchernegovski et al. 2018a; Ward et al. 2017).

A further benefit of offering Family Focussed Practice, which more indirectly benefits the offspring, was captured in Gregg et al.’s (2021) systematic review in which 5 qualitative studies (Maddocks et al. 2010; O’Brien et al. 2011b; Ward et al. 2017; Tchernegovski et al 2018a, 2018b) reported professionals’ reflections that involving the offspring and wider families increased not only the chances of the parent-patient improving but also of them

staying well. One participant in Ward et al., (2017) (page 3) was quoted as saying: *'We all know... that if you don't engage the family meaningfully, peoples' recoveries [are] really limited'* (Ward et al. 2017). This resonated with what one participant in my qualitative research reflected when discussing the value of supporting the wider family:

*'I think that when you look at the process of recovery like you can have all the medical side of things to get people to where they need to be but ultimately we are social people and we need to feel like a part of something and that helps people build resilience it helps people recover and have self-confidence, self-esteem and that kind of thing and feel part of something and wanted. And if you don't have family then in my view all that medical treatment isn't worth anything because once you've had that treatment and you let them out, they've got nothing coz they've broken all their relationships and they haven't been repaired you might as well walk them back straight in because it's pointless. Coz that's why people then get involved with bad relationships with negative peers and drugs and alcohol coz that's what happens because you've got nothing, you're isolated and it's not nice being lonely when you're in a normal frame of mind.'*

Although this benefit relates more directly to the parent rather than the offspring, there will certainly be indirect benefits for the offspring through having a more stable and better adjusted parent and there may be direct benefits too.

When thinking therefore, about whether, on balance, offering intervention for the offspring is appropriate, necessary, and worthwhile, there is increasing evidence that it is. Although the offspring in this research had attained resolution, the path had been tricky and participants reflected on how some sort of intervention or support would have helped them earlier in life, with one considering that it may still be of benefit now. The research literature on the benefits of widening focus from the patient-parent to the whole family, including offspring is growing, as is government interest in this. In England, the Carers Trust have taken a leading role in launching and establishing the 'Triangle of Care' in many NHS Trusts which provide mental health services (Hannan, 2013). The Triangle of Care captures the 'therapeutic alliance' between patients, staff and carers and sets related standards to ensure the identification and inclusion of carers as well as

support for them (Hannan, 2013). Internationally, recent literature reviews on Family Focussed Practice show positive outcomes for parents and offspring and given the reduction in risk of intergenerational transmission, intervention may have a positive impact on future generations too.

#### ***4.9.4 What are the barriers and potential facilitators to staff looking after the offender-patient-parent engaging with the offspring?***

As described in the previous discussion point, there is now longstanding and widespread acknowledgement both in government policy, and in the research literature, that ideally, for families where a parent has psychiatric disorder(s), the patient will be seen as a parent, not solely as a patient, and all family members will be given due consideration by clinicians. However, there are a range of possible barriers to healthcare professional engagement with offspring which may include passive omissions or active resistance by the professionals individually, challenges in organisational structures and job descriptions, and/or worries by clinicians in adult services, about their competence to engage with children and young people. Barriers may also exist in the form of reluctance or hostility to professionals contacting the offspring on the part of the parent-patient, in relation to children aged under-18-years, reluctance or hostility on the part of the adult with legal parental responsibility and, if ever consulted, reluctance or hostility on the part of the offspring. In addition, notwithstanding willingness to engage, there may be practical and resource barriers as secure hospitals tend to be some distance from the home communities and have no dedicated resource for ameliorating other barriers to engagement which may exist, for example if the offspring are in full time employment or have others for whom they are responsible.

The presence of barriers to Family Focussed Practice is evidenced in the challenges in translating the growing evidence base for this approach, in to practice (Lauritzen et al., 2014; Grant and Reupert, 2016; Grant et al., 2018). Although some of the experiences captured in my participants' accounts is historical and may not reflect current practice, it

was notable that there was only one positive account of participants' interaction with the healthcare professionals caring for their parent. This was when a participant said

*'I think my mum's consultant explained [the parent's mental illness] really well'.*

Other recollections were less favourable and included

*'I don't sort of remember speaking to a member of staff or anyone to explain what was happening'*

and

*'I wonder whether the hospital, whether they could have taken a more proactive approach to involving me'.*

In relation to the barriers to secure hospital clinicians engaging the offspring, participants expressed their own hypotheses. These included that it may be related to the parent-patient not having been the child's primary caregiver at the point of admission and of the now adult aged offspring not being the person whose 'name is down' with healthcare staff. Offspring noted that they were not being routinely contacted or invited to care and treatment planning meetings, for example. Not being part of the care team's perception of who needed to be contacted and involved was experienced by offspring as inconsistent with their own reality of being the one supporting the parent on the phone during their secure hospital admission or having been the one visiting them during school lunch breaks and directly exposed to the parental symptoms whilst the parent was in the community.

Offspring had some frustrations with the procedural challenges and time frames involved in getting information about their parent, even when their involvement in the patient's life was established, with one participant commenting

*'Leaving messages on a desk over a phone resulted in 15 or 20 questions never being returned... I just wish there was a way of accessing that information more easily.'*

The research literature supports the presence of several barriers specifically to healthcare professionals who are working in adult mental health services adopting a more family focussed approach. For example, in a recent systematic review of the literature Gregg et al. (2021) found evidence that a range of variables increase or decrease the likelihood of Family Focussed Practice being implemented. Healthcare professionals' attitudes were one such variable. There was evidence of some healthcare professionals having significant concerns about involving children in a more family focussed approach, considering it 'inappropriate or detrimental' to parent-patients (Sjöblom, Pejler and Asplund, 2005; Slack & Webber 2008; Maddocks et al. 2010; O'Brien et al. 2011b (all cited in Gregg et al., 2021)). Some professionals were less concerned by it in principle but did not consider it their responsibility, which again reflects issues with funding streams and organisations working with tightly defined populations to address a limited range of problems. For example, Adderley et al., (2020) discusses this regarding staff working with parents with psychosis, whilst Reupert, Maybery and Morgan, (2015), discuss this regarding GP practices, and Mason et al., (2017) look at the issue of silo working across mental health and substance use in the context of intimate partner violence. One's professional background and setting were found to be associated with likelihood of engaging with Family Focussed Practice. Social workers were most likely to adopt a Family Focussed Practice approach and there was some evidence that psychiatrists were also more likely to consider the family context than other disciplines (Gregg et al., 2021).

In a secure setting a potential barrier not frequently captured in the literature on more generic adult services, is the possible shame that the parent-patient may experience around the index offence and/or mental disorder, and the sense of distance between parent and child that this can create (Parrott, MacInnes and Parrott, 2015). My qualitative research indicated that the index offence can create a barrier for the offspring too, albeit in this case temporary, with one participant saying



*'I was so horrified that he lit the flat on fire that I just didn't even want to acknowledge that he was my father'.*

Another barrier or facilitator described for children under 18-years-old by social workers in Kalebic et al., (2020) was that of the child's other parent (or other current primary caregiver). This was echoed in some of the family dynamics described by participants. One participant explained how her grandparents ensured she maintained contact with her parent patient whilst she was a child, taking her for face-to-face visits in both secure hospitals and prisons, whilst two other participants' parent had emigrated with them, reducing scope for face-to-face contact, and adding a further barrier to any relationship by maintaining a narrative of the patient-parent not being psychiatrically unwell but rather 'attention seeking'.

Kalebic et al., (2020) also highlight the need for liaison between services regarding secure hospital patients and their children. The structure of services to meet the needs of one individual and to be specialised to this role, and in this case, one age group – children or adults, has resulted in repeated problems implementing Family Focussed Practice (McCartan et al., 2022). It may also have contributed to some of the barriers to Family Focussed Practice that emerged from some healthcare professionals not considering the wider family context of their patients to be their 'core business' (Reupert et al., 2015) or job role (Mayberry and Reupert, 2009). In one study, healthcare professionals working with adult parent-patients with psychosis fell into three groups, one of which felt that whilst 'parenting interventions might be worthwhile, they are not my responsibility' (Adderley et al., 2020).

Despite these barriers, some factors enhanced the likelihood of Family Focussed Practice. Workplace support in terms of guidance, supervision, emotional support and family focussed training were well evidenced to improve the implementation of Family Focussed Practice (Gregg et al., 2021). Family focussed assessment tools and other tools to facilitate implementation of Family Focussed Practice could positively enhance Family Focussed Practice, but could not ensure it occurred (Gregg et al., 2021).

Another challenge for healthcare professionals, and further potential barrier to them effectively adopting Family Focussed Practice, is that as the offspring grow up their needs will change. Services may engage with families at the start of the parent's hospital admission – with a family welcome meeting for example - and then feel that that aspect of care has been addressed, but if children are not in a place to engage with the parent at that time, or considered too young or too vulnerable to attend those meetings perhaps services could routinely revisit the patient's family structure as it evolves to ensure that family who are wanting to connect/reconnect with the patient are fully briefed as to how to interact with services. One participant in my research reflected that

*'I guess there's no standard way as to how families are involved'*

and there is perhaps a challenge for services in identifying this, especially when changes occur in the patient's network. One participant had a child of their own and identified the patient's grandchild as a possible motivating factor, so could be important in terms of the parent-patient's engagement in treatment as well as their wider social wellbeing. Indeed, in the quantitative project detailed in chapter 3, it was unanticipated how many other important relationships patients had with children other than their own, extending not just to grandchildren but also nieces and nephews.

Despite the barriers that the participants in this study had experienced, one held optimism looking forwards, especially in the context of services being more set up for remote interactions and the scope to improve the involvement of families in patient care. This is perhaps particularly pertinent in regional services like secure hospitals where families are more likely to live further away, but also in the case of young adults who may themselves have moved away and have other commitments, particularly between 0900 and 1700 on weekdays when most of the care team are available. Participants also wondered whether there would be scope for some online communication by email or other means to enable questions to reliably get through to the relevant clinician and for answers to be provided, where appropriate.

Barriers to healthcare professionals reaching out to the offspring of parent-patients are well documented beyond the material in this interview study (Stanley, 2003; Kalebic et al., 2020), which suggest that such barriers may also be present in the secure estate. What is encouraging though is that there are modifiable factors which can be tweaked to improve Family Focussed Practice, such as specific training and support from colleagues, including at a managerial level. Some of the challenges in the wider literature around Family Focussed Practice may be harder to overcome, given that they pertain to interagency working, and particularly to child services working with adult services, to ensure the whole family is taken care of. This is recognised as a barrier in the literature, including in Kalebic et al., (2020), where liaison between the child's social worker (where present) and the parent-patient's social worker is recommended, as well as more systemic changes such as joint training opportunities. The complexities of gaining consent from the patient and from the family and/or carers for more systemic approaches are notable and can comprise a barrier too. However, it is also hopeful that at least one participant in this qualitative research held optimism for future improvements in Family Focussed Practice and the suggestions made by that participant as described previously, add weight to the importance of coproduction when developing services.

#### ***4.9.5 Limitations and strengths***

There were very few participants in this research - just 4 offspring - and data saturation had not been reached. The participants had all experienced resolution and given the absence of data saturation it is impossible to say whether this is always the case, but it seems unlikely. Therefore, findings must be regarded as more tentative than is usual even for qualitative research. The second major limitation is that I was able to speak only at one point in time with people and this was generally years after the initial parental secure hospitalisation, which took place when they were at a different developmental stage.

Whilst I was careful to guard against my own biases, and record participants' unprompted perspectives verbatim, I cannot rule out possible biases entering because I went on to ask some specific questions. As the interviews were recorded and transcribed in full it was possible to note the extent to which questioning was similar across the interviews. The broad open question was presented very consistently to each participant. The follow up questions, although based on an interview schedule, depended on what the participant had already covered and had to be tailored during the interview process. This inevitably led to some differences in the exact questions asked and I was able to reflect on this when analysing the data, but key topics such as participant's experience of stigma were asked of everyone. Bias may also have entered at the analytic stage, where, notwithstanding blind identification of first level categories, which proved reliable, it is possible that my supervisor and I shared biases. It is also possible that there were biases introduced by the participants themselves, including who was (and who was not) happy to participate. Recall bias may also have been present. There was nothing I could do to ameliorate these biases, but they must be held in mind.

Despite the limitations to the model produced from this research, there are some strengths to be noted. Although only including 4 offspring voices, this research is the first to capture the offspring experience as told by them and offers the first insights into the experience from their perspective. Although small, the sample included men and women among both the offspring and parent-patients, and the offspring involved had had a range of primary care givers, including, but not always, the parent-patient. It is also encouraging that there were broad similarities between my research and published work in the related group of young adult offspring of parents with severe and enduring psychiatric disorder (Blake-Holmes 2020), yet also some novel findings in terms of this small group having attained resolution.

#### **4.9.6 Summary**

In this chapter I have described qualitative work, from which a model was generated, which described an offspring core concern of 'chaos and confusion' which was resolved through attainment of 'stability, security, and autonomy'. Stigma was not named by any of the participants in their response to the initial open question, transcripts of which were analysed using Grounded Theory. However, in the participant responses to the semi structured questions it became increasingly apparent that stigma had permeated much of their experience. It was possible, in this context to see evidence of stigma in several higher order categories which were present in the model – the core concern of 'chaos and confusion' in particular, and the barriers to resolution of this, as well as the offspring experience of health and social care professionals.

Discussion points which followed on from the model and exploration of the offspring experience of stigma included firstly, placing this model into the context of qualitative work with young adult carers who have a parent with a major psychiatric disorder, but who have not necessarily also presented the risk to others which for my population of interest required parental secure hospital admission, and who had also not necessarily experienced mandated parent-child separation. Similarities were evident between the groups with participants in both studies speaking about the need to have some control or autonomy in the relationship with their parent-patients and their struggles with parent-child role reversal. The Blake-Holmes (2020) study however provided a context in which one could see how potentially positive the parental secure hospital admission had been for the offspring in my study. Although health care staff had not always been perceived as interacting optimally with the offspring, the relief of the parent being physically safe and cared for became clearer in the context of the narratives of offspring whose parents had not had such an admission and who therefore had not had this period of effective respite in terms of the emotional toll of the parent being in the community, and for some, the practical caring responsibilities. This enabled me to reflect on the parent-child separation necessitated by the parent's admission as perhaps being an important facilitator of resolution rather than perhaps through the lens considered in chapter 2,

whereby the consequences of the separation were anticipated to be largely negative for the offspring.

The second discussion point in chapter 4 explored whether, given that the participants in my research had all attained resolution and were doing subjectively and objectively well, there was any need or justification for offering these offspring intervention from healthcare professionals and if so, what the barriers may be to this. The discussion identified that Family Focussed Practice (FFP), which would support the wider family, including the offspring, was well evidenced in terms of effectiveness, including in its scope to reduce intergenerational transmission of psychiatric disorder. Evidence came through in my qualitative work too of the importance of involving the whole family when providing care and treatment for parents with a major psychiatric disorder.

The third and final discussion point focussed on the barriers to healthcare professionals adopting Family Focussed Practice and included systemic challenges in promoting inter agency working. Even within the adult mental healthcare professionals there were barriers relating to their sense of efficacy in supporting the wider family, and for some a lack of belief that it is their role or responsibility, with a few healthcare professionals believing that involving the children could be 'detrimental' (Maddocks et al. 2010; O'Brien et al. 2011b; Sjöblom, Pejler and Asplund, 2005; Slack and Webber, 2008).

#### ***4.9.7 Conclusions***

This chapter therefore has described interview work with a population never previously studied in the research literature and has been able to provide a preliminary model to capture those participants' core concern and resolution of this using Grounded Theory methods. Examination of the model in the context of research with young adult carers has enabled important context to be derived regarding the possible positive effect of the parent-child separation mandated during a parent's secure hospital admission.

Discussion has also explored whether secure hospital patients' offspring should be offered some sort of support and concluded that there is a strong argument for this given

the evidence base for Family Focussed Practice and the needs evidenced in the qualitative work. There are barriers to this routinely happening in adult mental healthcare and there is now evidence of this also being the case within secure hospital care, which will need addressing if healthcare professionals are to provide a more attuned and responsive service to the offspring of their patients.

## **Chapter 5: Discussion and Conclusions**

### **5.1 Introduction to the general discussion**

This thesis has added to research knowledge because the experience of the offspring of parents who are, or who have been, detained in secure psychiatric hospital settings have hardly received any prior research attention, even though up to half of secure hospital patients are parents. This is despite, as explored in the thesis introduction, and revisited throughout the thesis, recognition of the power of adverse childhood experiences to affect later mental and physical health and social adjustment. Many studies of ACEs demonstrate their cumulative nature (for example, Chapman et al., 2004) and four or more ACEs is particularly associated with progression to later problems, as discussed previously in this thesis. The offspring of parents detained in secure psychiatric settings are likely to face at least four ACEs. They will certainly have experienced parental mental disorder and are likely to also have experienced parental substance and/or alcohol misuse (especially the offspring of fathers as described in chapter 3). The certainty of offspring having a parent who poses a serious risk to others may encapsulate any form of abuse to the child, and/or inter-parental violence, each of which comprise a further ACE. Parental separation is another ACE, which all participants in my qualitative research had experienced, and all parents will be physically, if not relationally, separated from each other by the secure hospital admission. For this overarching discussion, I restate the research aims and summarise the main findings of each of the three main avenues of inquiry that I took and highlight the main outstanding areas for discussion. After the discussion points, I consider the overall strengths and limitations of the research and the implications of the findings as they stand both for further research and for practice.

### **5.2 The thesis' avenues of enquiry, a recap of the research aims, a summary of findings, and introduction of discussion points**

In the first avenue of enquiry, as described in chapter 2, my aim was to complete a narratively synthesised review of systematic reviews on quantifiable offspring outcomes,



including problems, needs and strengths, associated with their experience of major parental psychiatric disorder(s), focusing on schizophrenia, affective illnesses, and personality disorder(s). The weight of evidence suggested a higher risk of poor offspring outcomes, including psychiatric disorder and/or behavioural, emotional, cognitive, or social difficulties compared to children who had psychiatrically well parent(s). No review explored child strengths and relatively few considered resilience promoting factors. I then placed this review into the context of other relevant research literature, which examined each of the other two main facets of the offspring experience –parental risk to others and parent-child separation.

The literature reviewing helped shed some light on the sort of problems that offspring of parents detained in a secure forensic hospital might face, but it also highlighted an important gap. A notable area which the papers included in my reviewing process did not focus on, perhaps because it is not usually included in the core group of ACEs researched was that of offspring experience of stigma. Stigma, as described in chapter 4, can operate at an intrapersonal level, through internalised or self-stigmatisation, at an interpersonal level (whether actual or anticipated) or at a familial, institutional, or cultural level. Since completing my review of reviews, two reviews have been published which consider this in the context of parental psychiatric disorder (Reupert et al., 2021; Dobener et al., 2022) and I am a named author on a PROSPERO registered protocol for a systematic review of the experience of stigma when a parent is incarcerated in prison (Kalebic et al., 2021), work from which has been presented as a conference poster (Thomas et al., 2022). Relevant information regarding the impact on the offspring, of the stigma which the parent experiences, has also emerged in two published qualitative studies, one which interviews the social workers of secure hospital patients, on which I am a named author (Kalebic et al., 2020), and one which interviews fathers in secure hospitals about their experience of being a parent (Wells et al., 2021). There are also some important insights in the Parrott, MacInnes and Parrott, (2015) paper on parenthood in a secure setting, which has been discussed previously in this thesis, but which I will examine again from an offspring stigma perspective in this discussion area. Stigma will therefore be the first discussion point in this chapter.

The second avenue of enquiry in this thesis employed quantitative techniques to achieve three aims:

1. To find the prevalence of parenthood in a 9-year admissions cohort from one regional secure hospital unit. The three prior estimates rest on point prevalence or coincidental data, so I sought to gain a more reliable figure through focussed calculation of a period prevalence. I found that nearly half of secure hospital patients in South Wales were parents and around two-thirds of the parents had at least one dependent child. Extrapolating from the prevalence figures in my study and taking the generally accepted figure of around 6000 specialist secure hospital beds in England and Wales, this indicated that between 5000 and 7000 children are likely to be affected by this situation at any one time.
2. To understand what could be ascertained from the clinical records in relation to characteristics of the parent-patient, including the nature of the parent's psychiatric disorder and offending behaviour before admission, thus offering an insight into what the child's experience of the parent might have been. I found that most patients, whether parents or not, had previously received psychiatric care but that parent-patients were less likely than childless-patients to have done so as children, less likely to have comorbid psychiatric disorders or to have self-harmed. The patterns noted in the offending behaviours of parent-patients showed that the index offence at least was likely to be seriously violent and the victim more likely to have been known to the parent-patient. Although child harm was unusual, this did flag a concern about intra-familial violence and risk of harm to the offspring (each of these being recognised ACEs), posed by the secure hospital parent-patient, and this risk to the offspring will comprise the second major discussion point presented later in this chapter.
3. To look at routinely collected data to understand more about the direct impact of a parent's secure hospital admission on parent-child contact. Although, by definition, the parental admission will necessitate separation, this work enabled

me to ascertain how any contact after the parent's secure hospitalisation related to prior contact. I found that for nearly a third of offspring there had been no contact in the 12 months prior to the parent's admission and this remained the case in the 12 months after; that left two-thirds of the offspring who had either been living with the parent or otherwise in contact in the 12 months before the parental admission. Those aged 18 years or older who had been living with their parent all maintained contact but nearly half of the dependent age children in the same situation lost contact entirely. The reasons for the complete loss of contact for so many of the dependent aged offspring compared to the adult aged offspring are likely various and complex but may include concerns on the part of adults in the lives of the under 18-year-olds about the risks to the child related to continued contact with the parent-patient. This further substantiates the reasons for discussing the risk(s) posed by the secure hospital parent-patients to the offspring in the second discussion point of this chapter.

The third and final avenue of research in this thesis employed qualitative techniques, hearing directly from the offspring about their experience. My aim was to interview adult-aged offspring who have had a parent detained in a secure hospital and to use grounded theory methods to find a theory and model of their experience. I found a core concern of 'chaos and confusion' emerging from the data, with resolution being attained through stability, security and autonomy. Although offspring who were interviewed did not name stigma as a problem for them, it was a theme which arose in various guises, such as embarrassment at the parent's behaviour, and/or the participants not having wanted to talk about this experience in childhood. This further substantiates stigma being the first discussion point in this chapter, building on the initial consideration of it in chapter 4. It seems particularly relevant to the dearth of knowledge about any needs of offspring themselves that, in this part of the research, I encountered several barriers to recruitment. Some of these were related to the pandemic as COVID precluded the study proceeding as planned with face-to-face interviews as well as having precluded the in-person relationship building with clinicians and parent-patients, which would likely have enhanced interest in supporting recruitment to the project. However, other barriers may be indicative of wider failures to help such offspring adequately and are highly relevant

to why there is so little prior information here. These barriers to recruitment are discussed in detail in the third discussion point in this chapter.

### **5.3 Discussion points**

#### **5.3.1 *Stigma***

##### **5.3.1.1 *Introduction***

Stigma was introduced in chapter 4 as despite not being named by any of the participants when speaking freely about their experience in response to the initial broad open interview question, stigma permeated their responses, and came through particularly strongly in the answers to the semi-structured questions. There was however interesting variation in the extent to which participants in my research perceived stigma to be operating in their lives. None mentioned it spontaneously, although some of the unprompted categories suggested it, including ‘embarrassing’ and ‘not wanting to talk about it’ and, when asked directly, some participants identified strongly with having experienced it. One participant, when asked directly, only readily identified stigma as having come from the patient herself, despite describing experiences and perceptions which appeared to capture significant stigmatisation.

As introduced in chapter 4, stigma can operate at several operational levels including:

- within the person (internalised or self-stigma)
- between people (for example direct stigma/experienced stigma, or perceived stigma, or anticipated stigma)
- within families
- within institutions, for example education, or the legal system
- at a wider cultural or societal level such as stigma in the media.

In this discussion chapter, I will relate the evidence that I detailed in chapter 4, regarding stigma operating at each of these levels for my participants, to the wider research literature including my literature reviewing as detailed in chapter 2 of this thesis.

#### 5.3.1.2 *Self-stigmatisation or internalised stigma*

In chapter 4 I presented quotations evidencing participants' self-stigmatisation in the context of courtesy stigma, including feelings of 'embarrassment', 'shame' and feeling different or apart. There was also evidence that one participant experienced what Dobener et al., (2022) termed as a 'self reflexive sensitivity' to experiences which might indicate that the offspring was also becoming psychiatrically ill, with her describing 'overthinking' experiences and wondering if they relate to a psychiatric disorder. However, for another participant they had become psychiatrically unwell and needed psychotropic medication. Further to the reflection in chapter 4 that there are likely challenges to balancing reading too much into normal fluctuations in mental state and not noticing that one is becoming unwell, it is worth linking this challenge to the evidence outlined in chapter 2, which substantiates that participants are at increased risk of developing psychiatric disorder compared to the general population.

#### 5.3.1.3 *Interpersonal stigma both experienced and anticipatory*

In chapter 4 I detailed how participants had experienced interpersonal stigma, including one who recalled

*you might get asked by your teachers 'oh what does your mum do?' You know, that's like a question what do they do? 'Oh well my mum's just in hospital'. Like, when they ask, 'oh she doesn't work?' ...There's always those assumptions about like what parents are supposed to be doing'.*

This resonated with comments from a 15-year-old girl who participated in Saunders' (2018) qualitative interview study of offspring of incarcerated parents. This participant explained how she didn't know how to answer questions about what her dad does for fear of being '*shamed and embarrassed and humiliated*' (Saunders, 2018).

#### 5.3.1.4 Stigma within the family

Again, stigma within the family was well evidenced in the participant interviews in chapter 4. One participant described how:

*'I didn't tell my dad that I'd told anyone else [about the mother's mental illness] or that I went to counselling because I felt like at the time my dad wouldn't understand'.*

In the literature on offspring who have a parent in prison, both offspring and their caregivers expressed the importance of privacy, with one 12-year-old boy being quoted as replying when asked if he confided in his friend

*'no, because I like to keep my business private'* (Nesmith and Ruhland, 2008).

In Yamamoto and Keogh's (2018) review of literature concerning children who had experienced parental psychiatric disorder it is reported that children were aware that relatives could stigmatise both them and their parents. Children who had a parent in prison described, through one qualitative research project, how they found that they were subsequently excluded from their extended family, which they said was 'sad and confusing' (Saunders, 2018).

Yamamoto and Keogh, (2018) reported children having been told not to speak about the parental mental illness, to others, by the unwell parent. Wells et al., (2021) undertook qualitative research with fathers who were detained in secure hospitals and identified mental health stigma as the biggest barrier to the father seeing their children, due to them struggling to know how to convey their placement in hospital and their mental disorder to their offspring. Parrott, MacInnes and Parrott, (2015) found that fathers in secure hospitals cited their own shame around their offending behaviour as a reason not to contact their child at all.

#### 5.3.1.5 Institutional stigma

One participant gave a particularly striking description of how institutional stigma had played out in a school environment, when describing how teachers had not responded to her plea for help through a letter to santa

*‘In the letter I actually wrote about everything that was going on at home, like that I was afraid to go home, and I remember writing about my dad [the unwell parent]. And I put it in the box, and I was hoping someone would read it but no one ever did ... and I never did anything after that.’*

Evidence from offspring who had a parent in prison was of more overtly negative responses from teaching staff with participants in one qualitative study describing how teachers would tell them that they would ‘end up’ like their incarcerated parent (Saunders, 2018). Offspring reported feeling ‘angry and humiliated’ when teachers compared their behaviour to that of their imprisoned parent (Saunders, 2018).

In a qualitative research project with the children of imprisoned parents in Scotland, (Lockwood et al., 2021) a child spoke of being

*‘treated more like a prisoner than the actual prisoners are. Walking in... your name gets shouted and you are told to queue, all orderly. And I’m like, “I didn’t even do the fricking crime mate. Why am I getting shouted at?” (page 11)*

#### 5.3.1.6 Cultural or societal stigma

In chapter 4 I outlined how cultural stigma most explicitly came through for my participants who had experienced living in both the United Kingdom and a contrasting culture, and whose well parent held views which were attributed by the participant to the parent’s cultural background. The participant said

*'mental illness is ... not seen as a thing, it's just someone being weak .. or.. attention seeking'.*

Another participant described a different type of societal denial of the impact of a parent's psychiatric disorder saying

*'where I lived it was a working-class area, pretty much majority was council estate and back then it was normal to grow up in a bit of chaoticness'.*

A third participant spoke of awareness within the community of what her parent had done in terms of his offending behaviour. Whilst this happened in the context of mental illness, this wider societal awareness of an offspring's family history is also evident in the literature concerning offspring of an incarcerated parent. Here, children's worries have included sharing a surname with the parent who had offended, saying that they would change their name when legally old enough (Saunders, 2018). Participants in this study reported how although they were not named in media coverage of their parent's crime, it was often apparent to members of the public that they were related, especially when they had public facing work roles in which their name was displayed (Saunders, 2018).

#### *5.3.1.7 Bringing together the evidence on the importance of stigma*

Stigma can be seen operating at a range of levels in the lives of the offspring of parents in secure hospital settings, with evidence from my work resonating with prior studies which examined the children of parents who either had psychiatric disorder(s) or who had been prisoners. Although this prior literature is confined to examining offspring experience of stigma with respect to either parental mental illness, or imprisonment, it is consistent with my research involving the offspring of secure hospital patients.



### **5.3.2 Risk of harm to the offspring of secure hospital patients**

#### **5.3.2.1 Introduction**

Risk can be thought of in terms of the ACE categories discussed in chapter 1, and when offspring are aged under 18 years, social workers and other professionals will be most attuned to possible physical, sexual, and/or emotional abuse of the child, as well as neglect. At an interpersonal level, such as between parent and child, the key risk factors for abuse include parental psychiatric disorder, substance misuse and inter-parental/intimate partner violence (Austin, Lesak and Shanahan, 2020), thus highlighting an increased risk for the offspring of patients in secure hospitals. The consideration of all risks to the offspring presented by their parent being a secure hospital patient is beyond the scope of this discussion point, so I focus on the following three areas:

1. The risk to the offspring of their own mental health being adversely affected. This was a key outcome from the review of systematic reviews described in chapter 2 and came through in the qualitative work described in chapter 4. This risk will be the first area of risk to be discussed below.
2. The risk to the offspring of being physically harmed by the parent-patient. The quantitative work in chapter 3 revealed some very real risks of this happening, especially during the index offence itself. This is the second point explored below and particular attention will be paid to the risk to offspring from mothers given the finding in chapter 3, that mothers who are secure hospital patients are more likely to have harmed a child than any other secure hospital patient group.
3. The third and final point within this area of discussion to be explored below, is the risk to offspring of having been emotionally abused or neglected in the various forms this can take: physical, emotional/psychological, educational, or medical. This is discussed in the context of evidence of offspring having experienced these ACEs during the qualitative research described in chapter 4.

I will address these points in turn before concluding this area of discussion.

#### *5.3.2.2 Risk to the offspring of developing mental disorder*

The first risk to the offspring in relation to their experience of being the child of a secure hospital patient to be discussed is that of them also developing a mental disorder. This intergenerational risk was a prominent feature of the literature reviewing in chapter 2, when looking specifically at outcomes for offspring of a parent with a psychiatric disorder, but also when examining other potential facets of the experience of offspring of secure hospital patients, including risks associated with experiencing inter-parental violence and in certain circumstances when separated from one's parent.

In relation to the risk of psychiatric disorder in offspring of a parent with psychiatric disorder, the presence of the increased risk is well established, as discussed in chapter 2 (Mendes et al., 2011; Rasic et al., 2014; Lau et al 2017), and additionally reflected in research beyond that review (for example, Landstedt and Almquist, 2019). For offspring, there is both the genetic risk of transmission (Gejman, Sanders and Duan 2010; Smoller et al., 2019; Poletti et al., 2020) but also the risk emanating from the environmental variables often associated with parental mental disorder, such as instability in the home environment, conflict at home, parental unemployment and financial concerns (Plass-Chistl et al 2017), which are also often transmitted from one generation to the next (Landstedt and Almquist, 2019). Bournsnel, (2011) found that parents with psychiatric disorder(s) had concerns that seeking support from professionals may bring them on to the radar of child protection services, which had previously been reported, and which may prevent them from reaching out (Darlington & Feeney, 2009). However, Bournsnel, (2011) also reported evidence that parents with psychiatric disorder felt that their parenting was impacted by their own parents' poor mental health, and by abuse which they had suffered in both childhood and in adulthood, further indicating possible intergenerational patterns. Parents with psychiatric disorder may also experience one or more other difficult circumstances such as unemployment, financial struggles, and/or

intimate relationship problems (Goodman and Gotlib, 1999). Boursnell (2011) also provided evidence that children growing up in a family in which one or both parents have a psychiatric disorder, learn behaviours which do not then equip them to practice optimal parenting themselves. There are therefore a range of mechanisms which increase offspring susceptibility to mental disorder, including their genetic vulnerability, but also including learned behaviours, and the possible co-occurrence of an abusive home environment, and reduced family functioning (Wiegand-Grefe et al., 2019; Radicke et al., 2021). These are all exacerbated by the unwell parent patient being at risk of hiding the difficulties for fear of losing custody or being stigmatized (see earlier discussion point), although the other parent may be a source of support for the child which can be beneficial (Collishaw et al., 2016).

The risk of the offspring of secure hospital patients developing mental disorder was also indicated to be increased when looking at another facet of their experience - the parent-patient's risk to others, which I examined in part through offspring exposure to inter-parental violence. Kimball's (2015) review found associations between exposure to inter-parental violence and an increased risk of psychiatric disorder in the offspring, specifically naming anxiety, depression, PTSD and/or attachment disorder. Risks to offspring relating to the research literature on parent-child separation similarly indicated an increased risk of offspring psychiatric disorder in certain circumstances. In the context of parent-child separation through child evacuation, there was evidence of an increased risk of mild and more severe depressive symptoms (Pesonen et al., 2007). Although the overall risk of inpatient psychiatric admissions in adulthood did not appear to be associated with childhood evacuation, adult women who had been evacuated were more likely to be admitted to hospital due to an affective illness than adult women who had not, additionally revealing a gender difference in vulnerability to this experience (Santavirta et al., 2015). In the context of parent-child separation due to parental death, there was evidence of an increased odds of offspring psychiatric disorder, but the pooled effect size was small (McKay et al., 2021). In the context of parent-child separation due to parental military deployment, risks to the offspring again included increased

psychiatric morbidity (Gorman 2010; Millegan et al 2013; Williamson et al 2018; Cunitz et al 2019). A range of factors will impact on this risk to the child including inherited factors, but also a range of environmental ones, including risk factors associated with parental psychiatric disorder, offspring violence exposure, adversity exposure, and the presence or absence of the other parent and quality of support if present.

Given that the literature presents evidence of increased risks to the offspring of developing mental disorder related to all three main facets of their experience – parental psychiatric disorder, parental risk to others and parent-child separation, it is a risk which one might anticipate applies to the offspring of secure hospital patients. The participants in my qualitative research showed awareness of such a vulnerability, with one saying

*‘it’s on our heads’*

and another having already experienced mental disorder and having received treatment. The participants were however, also conscious of the protective factors that they had experienced in terms of having had a

*‘very different upbringing’*

and their personal strengths in terms of being resilient. This balanced perspective may be important in finding that middle ground between complete denial of the risk and being overly sensitive to normal fluctuations in mental state, as discussed in the ‘stigma’ discussion point above. Also relevant here is the risk of stigma leading to both parent-patients and offspring behaving secretively about the parent’s illness which then precludes help seeking and opportunities to mitigate the risk (Reupert et al., 2021). When families do not seek outside support and do not speak within the family about the parental psychiatric disorder, there is a risk that the situation is perceived as ‘normal’ by the offspring, which then precludes impetus to seek any alternative trajectory, enhancing risks of repetition in the future. It was notable that for the participants in my qualitative work, part of resolution was gaining a wider perspective and moving past their earlier perceptions of their childhood as having been ‘normal’. This was tempered with

acceptance that in terms of their relationship with their unwell parent, there was a limit to how 'normal' this could become, but 'normality' was in the refocused context of understanding that the chaos and confusion of their childhood was not normal, even if it was at the time, in their words, '*my normal*'.

When thinking about the offspring risk of developing mental disorder, it is worth balancing concerns by going back to the promising results of interventions relating to the modifiable factors. As mentioned in the discussion in chapter 4, a 40% reduction in the offspring risk of developing the same disorder as their parent has been demonstrated through relevant interventions (Siegenthaler, Munder and Egger, 2012). For offspring who have a parent detained in a secure setting, the challenge of parent(s) not wanting to reach out to services for support is no longer an issue, and although earlier intervention for the offspring may have been preferable, healthcare professionals in secure settings are relatively well placed to respond to offspring needs. Despite secure hospital staff being well placed to respond to offspring, there are many real barriers to them engaging with Family Focused Practice as discussed in chapter 4. In short, these barriers include any stigmatizing beliefs held by healthcare professionals, any worries on their part that they are not equipped to support the offspring in addition to the parent, and systemic problems which arise from services not being set up to work with different generations.

#### *5.3.2.3 Risk of physical harm to the offspring*

Any parent admitted to a secure forensic psychiatric hospital has harmed and/or is at explicit risk of harming others at the time of admission, and for those with children, the people at risk are likely to include any offspring. Chapter 3 captured the seriousness of the parent's index offences and indicated that the victim was more likely to have been known to the parent-patient than was observed in the childless patients. This points to a real risk of the child having been a victim, or witness, in the index offence, or at least having known the victim. Notably, mothers were more likely to have harmed a child than childless women in this sample, although numbers were small.

To recap the main relevant findings of chapter 3 - of the 17 mothers detained in the secure hospital in the 9-year cohort study; 7 (41%) had never harmed a child, 5 (29%) had one or more convictions for harming a child and 5 (29%) had been documented to have harmed a child but this had not resulted in a criminal charge or conviction – so nearly 60% of the mothers had harmed a child whether resulting in a criminal conviction or otherwise evidenced. By contrast, of the 10 childless women in the cohort, only one (10%) had ever been documented to have harmed a child and this had not resulted in a criminal charge or conviction. Having harmed a child was consistently low across the men in the cohort, with 13 (22%) fathers and 15 (19%) of childless men. The significantly higher proportion of mothers who had harmed a child appeared concerning and I will explore this more below.

To understand this result in more detail, I examined the wider picture of women's interaction with the Criminal Justice System. One explanation for the higher proportion of women who had harmed a child in this secure hospital cohort might be that women who harm a child are more likely to receive a hospital disposal than a custodial sentence. There is some evidence for this at the most extreme end of child abuse, with one study of adults convicted of infanticide in England and Wales reporting that most men (n=71, 96%) were sentenced to detention in custody, whilst most women (n=28, 74%) received community or hospital disposals (Flynn and Shaw, 2007). Looking at national figures, the Ministry of Justice analysis of sentencing disposals indicates that statistically men are more likely to receive a custodial sentence than women convicted of a similar type of offence (Hopkins, Uhrig and Colahan, 2015). A limitation here, given the concern about risk to children, is that all 'violence against the person' was analysed as one group, with 20% of men and 7% of women receiving a custodial sentence (Hopkins, Uhrig and Colahan, 2015). However, the increased odds of men receiving a custodial sentence compared to women did hold true across all offence groups (Hopkins, Uhrig and Colahan, 2015).

Another explanation might relate to the types of criminal behaviour for which women are more likely to be prosecuted. A document examining 2019 statistics on women and

the Criminal Justice System (Ministry of Justice, 2020) examined which indictable offences had the highest proportion of women being convicted and reported 'cruelty to or neglect of children' as the highest, with 60% of the 427 people convicted being women. This was reported to be consistent with a previous analysis in 2015. Although proportionately more women were convicted of this offence, only 14% compared to 34% of males received a custodial sentence, which again suggests that perhaps women are more likely to receive a mental health disposal. In the same document, two of the three summary offences with the highest proportion of women being convicted related to children. The highest of these was 'truancy' for which women made up 71% of 19,600 convictions in 2019, followed by 'drunkenness in charge of a child', in relation to which 67% of the 162 people convicted were women (Ministry of Justice, 2020).

Women are perhaps more vulnerable to both committing and being convicted of offences involving harm to a child due to comprising the vast majority of lone parents in the country. Notably, of lone parent households with only dependent aged children in Wales, in 2021, n=227 (87%) involved lone mothers and n=33 (13%) lone fathers (total 260, 100%) and the proportions involving women was even higher in England at 91% (Office for National Statistics, 2022).

In the cohort described in chapter 3, the numbers of lone parent-patients with only dependent aged children were small in both the father-patient group (n=2) and the mother-patient group (n=3), although even here proportionately there were more lone mothers at 18% compared to 4% for fathers. This may relate to the prior histories of the patients, given that 40% of the mothers had had a previous medium or high secure hospital admission, which is much higher than in the general population and therefore the proportion of mothers who had retained lone mother status might be anticipated to be lower than that in the general population. A previous secure hospital admission and parent-child separation, is likely to have resulted in loss of parental responsibility (as detailed in chapter 3), perhaps leaving smaller proportions of lone parents at the time of the current admission.

In thinking about lone mothers and risks of physical harm to the child, it is perhaps useful to reflect on the findings reported in the systematic reviewing in chapter 2 regarding outcomes for children separated from a parent due to parental military deployment. All three systematic reviews which examined child abuse and/or neglect by the non-deployed parent during parental deployment, found an increased prevalence compared to civilian children (Gibbs et al. 2007; McCarroll et al. 2008; and Rentz et al. 2007). Although this would represent a risk from the parent who was not admitted to a secure setting, it is still a potential risk of direct harm to the child resulting from the unwell parent being removed from the family home (in the case of two parent families). It is additionally relevant here as most soldiers who are deployed are men, so most of the partners remaining at home and becoming a sole carer for the children, will be women.

A further explanation as to why mothers may be more at risk of harming a child, lies in the risk to women of postpartum psychosis. Although rare, it is a psychiatric emergency, and carries risks to the mother and to the offspring including death (Bergink et al., 2011). Although there have been a few case reports of fathers becoming acutely psychiatrically unwell in the postpartum period (e.g. Shanhani, 2012), postpartum psychosis is generally considered to be an illness which affects women. Even among women, it is a very small proportion (1-2/1000) who in the days, or within early weeks, after delivery are affected (Kumar et al., 1995; VanderKruik et al., 2017). Although rarer than postnatal depression or baby blues, the risks to the mother and her offspring necessitate early recognition and treatment, and when this is absent, harm to the child can occur (Bergink et al., 2011). Symptoms vary but include disorganized behaviour, cognitive impairment, mood disturbance, delusional beliefs, and hallucinations (Brockington et al., 1981; Sit et al., 2006; Kamperman et al., 2017). Delusions may involve the newborn, which can escalate risks (Osborne, 2018) and delusions may include thoughts that the baby will come to harm (Chandra et al., 2006). It has been reported that approximately 4% of women who experience postpartum psychosis will commit infanticide (Parry, 1995), so the numbers are very small for this extreme adverse outcome, but those women who commit this offence are likely to warrant secure psychiatric care. As indicated, this is a psychiatric illness, which affects very few women who deliver a child, however, given the potentially serious outcome, in conjunction with the small number of women admitted to secure



hospital beds compared to men, the occurrence of this gender specific psychiatric illness may help explain the higher proportion of mothers who have harmed a child, than childless women, or men, in the 9-year cohort study of secure hospital patients.

The finding of mothers being more likely to have harmed a child than any other patient group analysed is concerning but this knowledge can be used to potentially prioritise the offspring of mothers in secure settings for assessment and support if needed. The finding should also be understood in the context described above, considering both that women are far more vulnerable to this type of offending behaviour, due to their increased likelihood of being a primary caregiver, especially a lone primary caregiver, and also considering that of all those convicted, women are more likely to receive a non-custodial disposal, and therefore potentially a hospital order.

Evidence pertaining to the risk of physical harm to the offspring was found in the qualitative research in chapter 4 of this thesis too. In the work described in chapter 4, adult aged offspring gave firsthand accounts of their experience, enabling a model to emerge from the data, which showed a core concern of a chaotic and confusing experience, which could be resolved through a move to stability, security and autonomy. Although none of the participants described being physically or sexually harmed by the parent-patient, there was evidence of worries and fear of being harmed by the parent. One participant said they were unsure if their parent might

*'stab me'*

whilst another said

*'he was really, really, scary like, coz you don't know what he's thinking. And then you think like... he could hurt me, like he could'.*

There was also one example of the parent having threatened to kill the participant's partner when they were still at school, which resulted in police involvement. The participant recalled

*'I had my first ever boyfriend and my father said to me erm, er 'I'm going to kill [him] and I know exactly where to bury him'.*

It is worth considering that the recruitment to this study was after the parental psychiatric admission and so offspring killed in the index offence or adopted at, or prior to, that time could not have been involved. Similarly, offspring with no contact with the parent-patient would not have been easy to locate to recruit to the study so this may have had the effect of biasing the sample to offspring who had not been harmed physically or sexually by the parent-patient. There is evidence from a large cohort study that offspring of parents who have a mental illness are at an increased risk of injury (Nevriana et al., 2020).

#### *5.3.2.4 Risk of emotional abuse and/or neglect*

The adult offspring accounts from the work described in chapter 4, also indicated that as children they had been subject to various forms of neglect and a few examples that might comprise emotional abuse, such as exposure to upsetting situations in the context of acute psychosis and the parent being physically absent whilst in the secure hospital. The experience of threats to a partner as described above would constitute emotional abuse also. In terms of offspring being neglected there was evidence of physical neglect with one offspring providing a retrospective report of having routinely been hungry to the point of developing a

*'prisoner complex'*

around food. The absence of food was secondary to poverty, which itself has been established to reinforce the clustering of ACEs in childhood (Lacey et al., 2020). Another example of neglect was in two participants' accounts of not having been adequately supervised due to parental intoxication, even as toddlers – one participant described

*‘there’d be times when she’d be sort of like passed out’.*

Educational and medical neglect did not feature strongly in the offspring narratives in my qualitative work. The literature on the children of parents with a mental illness has often reported bullying by peers and teachers (Dobener et al., 2022), as has the literature on children with an incarcerated parent (Myers et al., 2013). However, for the participants in my qualitative research, school provided a place of relative respite, and at times a source of trusted adults to confide in, although as detailed in the ‘stigma’ discussion point, there was one occasion when a teacher did not act on a disclosure made by the child. Medical neglect was not widely reported by participants in my qualitative research, although missed diagnoses denied the offspring timely input and support. Given that the nature of the difficulties might have been expected to be picked up in school and diagnosed by an Educational Psychologist, this is perhaps more evidence of inadequate care and attention, and perhaps stigma, from school.

#### *5.3.2.5 Bringing together the risks to the offspring from the unwell patient*

When thinking about possible harm to the child from the secure hospital parent-patient, in one respect, intervention at this point may be too late in the case of children who have been seriously harmed or even killed in the index offence. However, even then there may be siblings who can be supported, although the preference would clearly be to prevent such harm occurring. It may be beyond the scope of secure hospital staff to have a role in this unless the patient has had a previous admission. However, the adversities that the offspring face, which comprise part of their vulnerability to being harmed, and also part of the parent’s vulnerability to harming the child, could be identified and intervention could be offered in a more preventative manner.

In thinking about more preventative approaches, some of the vulnerabilities elicited, such as poverty and adequate support in the postnatal period have received government interest. Welsh Government had sought to end child poverty by 2020 (Welsh Government, 2015). However, the most recent statistics published by Welsh Government

indicate that a child in Wales, in 2020, had a 13% likelihood of being in persistent poverty, meaning having been in poverty for at least 3 out of 4 consecutive years (Welsh Government, 2022). In relation to perinatal support for families in Wales, Uned Gobaith (Unit of Hope), opened in April 2021, providing perinatal inpatient psychiatric care to mothers and their babies, which has enabled the most seriously unwell mothers to receive inpatient treatment with their infant, in Wales.

For older children, school is a key opportunity for emotional and behavioural problems to be picked up early and for support to be offered. The government's green paper on Transforming Children and Young People's Mental Health Provision (Welsh Government, 2017) placed schools at the centre of aspirations to develop a 'culture of openness around mental health' which is an approach commensurate with tackling stigma at an institutional and cultural level and is being actioned through the Whole School Approach (Welsh Government, 2021). The Whole School Approach in Wales provides a Framework which all state funded schools are required to pay regard to, and is intended to work in conjunction with both the NHS Together for Children and Young People (T4CYP(2)) and with parents and carers, to provide a whole system approach to improve the well-being of children and young people in Wales (Welsh Government, 2021). One of the four purposes of the new Curriculum in Wales is to develop 'healthy confident individuals', which again emphasises a systems wide approach to improving child well-being in Wales (Welsh Government, 2020; Welsh Government, 2021).

### **5.3.3 Barriers to recruitment to the qualitative research**

#### *5.3.3.1 Introduction*

The qualitative work in this thesis, as detailed in chapter 4, sought to hear from offspring of parents currently, or previously detained in secure psychiatric hospital(s), about their experience. As this was such a new area of study, I decided not, in the first instance, to seek participants under the age of 18 years. This was for three reasons. The first was that in such a new field it seemed wise to find out whether adult participants experienced any

distress by telling their story, and if so the likely extent of this, so as not to risk opening up a conversation about likely traumatic experiences with children in situations with uncertain levels of potential support and mitigation. The second reason was that I anticipated that the other relatives and perhaps any professionals involved would have reservations about the child participating, particularly in terms of their well-being and privacy. This had potential scope to make such recruitment very challenging, and given the untested nature of the research, perhaps inappropriate. This leads to the third reason, which was the likely challenges in involving under 18 year olds in an ethically robust way. For these reasons, I anticipated that it would be difficult to obtain the necessary ethical and research and development approvals (as well as approvals from parents/carers and young people) for the study, and therefore chose to focus on adult children, where these issues were perhaps less of a concern. Despite only seeking to recruit fully consenting adults who had capacity, recruitment to the interview study proved extremely challenging and a range of barriers became apparent. These included the following:

- factors relating to the participants themselves
- factors relating to the participant's parent where they were involved in the process of recruitment
- factors relating to the clinicians who supported recruitment.

The problems of recruitment were exacerbated, but not wholly explained by the emergence of the COVID-19 pandemic at the beginning of my recruitment programme. I will consider each potential barrier in turn.

#### *5.3.3.2 Possible barriers to recruitment relating to the potential participants themselves*

As described in chapter 4, I identified twenty-two people who were in a position to give a first-hand account of the experience of having a parent in a secure hospital. Eight people were certainly made aware of the project, of whom four completed interviews. For a further four, the parent-patient was certainly aware of the project and said that they

would discuss the research with their child(ren), but I never heard from the children directly, and do not know whether they received the project information or not. A further ten people were therefore eligible to participate but as far as I know, never knew about the project. This lack of awareness of the project was for a range of reasons as detailed in chapter 4. Despite asking to receive feedback on what led people to decide not to participate, I did not receive any feedback directly from the potential participants who chose not to take part.

The practical barriers to research participation cannot be over-estimated. Initially I was asking people to travel to meet me for interview, perhaps over long distances. While we had agreed to reimburse travel costs, potential participants were likely to be juggling paid employment with young families of their own and I was offering them no compensation for any other incurred losses, such as their time or having to pay for extended hours of childcare. Researchers have noted that projects requiring additional effort and resources on the part of participants over and above that required in their routine health service use is not readily taken up (Huntington et al., 2017). My project had perhaps the double barrier that not only was it an ask on participants' time, but it was also not directly related to their personal healthcare. Although, through the project, I hoped to improve the experience of people in a similar position in the future, the absence of a tangible benefit for the potential participants may have made the project feel less relevant and/or less of a personal priority. A review of reviews and thematic analysis of barriers and facilitators to participation in clinical research identified a theme around 'hope' which was present in participants completing research relating to cancer but less so for other areas, particularly those which recruit notionally healthy volunteers, as was the case in my study (Rodriguez-Torres et al 2021).

My survey work in chapter 3 would suggest that around 25 adults would have experienced having a parent in the South Wales medium secure hospital over the period of recruitment. It was therefore likely that there were some eligible offspring who I was unable to engage in thinking about participation. The work in chapters 2 and 3 of this thesis explored the situation of children of secure hospital patients and some of the features of their experience might bring them in to the category variously described as

being 'hard to reach', 'disadvantaged' or 'marginalised' and this may apply to those who were aware of the project and chose not to participate as well as those who were beyond contact by the research team (Tully et al., 2021). Offspring who have a parent with a psychiatric disorder have been described as an 'invisible' population (Cowling, 1999). There is research indicating that people in such situations are less likely to be inclined to participate in research (UyBico, Pavel and Gross, 2007; Martin et al., 2016). Further, socioeconomically disadvantaged people are less likely to participate in research than those who are more socioeconomically advantaged (Patel, Doku and Tennakoon, 2003; Henrich, Heine and Norenzayan, 2010), which may be relevant to the well-functioning, economically stable, self-selected group of participants who did participate in my qualitative study. Given that people with psychiatric disorder(s), and therefore by extension their children, are at increased likelihood to be in poverty, and socio-economic patterning continues into adulthood (Gould, 2006), it is possible that some potential participants were in this group.

Another specific barrier, identified by Tully et al., (2021), was uncertainty in the participant's mind about what would be expected of them in any proposed research. The exploratory nature of my project resulted in my asking participants to tell their story, however they wished. Whilst this sought to hand control to the participant to say as much or as little as they wished, and about whatever aspects of their experience they felt were relevant, this may have left them feeling uncertain around what I, as a researcher, expected or wanted from them. Anxiety around 'getting it wrong' may also have had a part to play, which links to concerns about offspring sense of stigma, which I have already discussed.

A systematic review on 'reaching the hard to reach' in epidemiological studies identified further barriers to recruiting socially disadvantaged participants (Bonevski et al., 2014). Participant beliefs or attitudes, which were evidenced as being barriers of relevance to this group, included mistrust of research and/or researchers. This may in part explain why the participants I was able to interview were disproportionately highly educated. Another barrier identified in this review was participant fear of authority (Bonevski et al., 2014). The previous experience of authority figures for the offspring of secure hospital

patients will have been varied, but for all of them, at least one of their parents is detained by legal powers and processes authorised by the state.

Bonevski et al., (2014) also described a fear within the participant of being 'publicly exposed' as being a potential barrier, and this may relate to a fear of being judged, which was also reported by (Blitz et al., 2013). I explicitly pre-warned potential participants, in the participant information sheet, that I may ask about topics like substance use, and their own contact with police/probation. Although it was also explicit that, in the event of agreeing to an interview a participant could discontinue at any point, or decline to answer any specific questions, it is possible that awareness of these topics as being of interest to the researcher might have been off putting.

#### *5.3.3.4 Possible barriers to recruitment through the potential participants' patient-parent*

I was seeking to recruit adults and, thus, people who must have the freedom to make up their own mind about participation in research which relates to them. The NHS Ethics approval for the project did not require the parent-patient's consent to recruit the adult offspring to the research. However, the reality for some potential participants was that clinicians did not have direct contact with the offspring. I was therefore reliant on the parent-patient agreeing to make the child aware of the project or passing on the offspring's contact details to the clinical team or to me directly. Previous researchers have experienced the parent's agreement being a key barrier to offspring recruitment to research, such as mine, in which some of the discussion relates to the offspring experience of the parent (McCormick et al, 1999).

It would be interesting to explore with clinicians in another study the various reasons they had for not having direct links to someone as close as a son or daughter of someone in such serious circumstances. From conversations that I had with parent-patients I sensed some suspicion of the project and why I wanted to speak to their offspring. This perhaps slightly suspicious or at least seemingly overly cautious response, was not unrelated to the parental psychiatric disorder, which complicated things further. Clinical staff who had spoken to the parent about their offspring being involved in the project



were sometimes able to give me feedback when the parent had declined to make their son(s) or daughter(s) aware of the project. Most frequently reported was a parental belief that the offspring was too busy, and the research would place undue burden on their time or prove an unhelpful distraction from their work or study. For participants a sense of being too busy to participate has been found to be a barrier before, and especially for participants with more psychosocial stressors (Vercruyssen et al., 2013; Brown et al., 2014). Other responses from patient parents included that the parent was due to move on from the secure hospital and did not believe that their child(ren) would want to think about the period during which their parent had been an inpatient, and/or that the child(ren) had experienced life stressors, and therefore the parent did not want them contacted about the research. It is possible that some of these parental responses may reflect the parent's own difficulty thinking about either their time in secure care or thinking about their child thinking about this. A qualitative study by Parrott, MacInnes and Parrott, (2015) described how parent-patients feel distanced from their children by a sense of shame in their circumstances, which by definition will make it more difficult for parents to encourage their child to share their experience when this encompasses their own circumstances. Indeed, the central question in my research was for the offspring to tell us about their experience of having a parent in a secure hospital. Parrott, MacInnes and Parrott, (2015) also describe a 'reliance' by the parents on professionals to manage the relationship with their child(ren) for them. This may make independent decision making on the parent-patient's part, to offer their child the opportunity to talk to a researcher about their experience, more daunting and in effect prevent them from being able to do this.

#### *5.3.3.5 Possible barriers to recruitment through staff reluctance or limits*

The third group of people in relation to whom barriers to recruiting participants may have arisen is the clinicians working with the parent-patients. Clinical staff were unfailingly supportive of the research and in agreeing to identify potential participants to the research team. However, despite the aspiration that all eligible participants would be made aware of the research project, there were one or two occasions when staff

working with either the parent and/or the adult offspring told me that they thought it was inappropriate to discuss the research with them at that time, variously because the parent was 'not doing well', or that they considered that the adult offspring was 'too fragile'. These sentiments were undoubtedly well intentioned, but the research literature suggests that the concerns may be founded in instinct rather than evidence. For example, it is well evidenced that asking about suicide in either clinical or research settings does not increase risk of harm to self but, on the contrary, is experienced as helpful (Dazzi et al., 2014). Bonevski et al.,'s (2014) review cited 'paternalistic beliefs' among healthcare professionals as a driver for restrictive gatekeeping behaviour, which itself is underpinned by assumptions that more deprived groups lack the time, interest or ability to play an active part in research.

In a qualitative study with social workers from a medium secure hospital, some of the social workers spoke of conflict between the parent-patient's wishes and preferences, and those of the family, specifically the children (Kalebic et al., 2020). This may have resulted in a barrier to the social workers making the adult offspring aware of the research project, especially if the social worker knew or suspected that the parent may not be comfortable with this, even though parental consent was not required. The social workers may also have been trying to protect the parent patient in case of any negative response from the child. The same study refers to social workers trying to balance supporting a patient who wishes to engage with their family, with preventing that family contact, if facilitated, from impacting negatively on them. There may also have been a tension between the social workers being employed by services primarily tailored to meet the parent's needs rather than the wider family, including the offspring. This systematic set up was identified as a barrier to family focussed practice in the discussion in chapter 4. It has also been identified that healthcare professionals involved in caring for the parent may anticipate that any offspring would have a dedicated support worker or social worker for themselves, even though this is not necessarily the case (Kalebic et al., 2020). The social workers involved in supporting recruitment to my qualitative research may have been cautious about being seen to push the research if the parent-patient expressed any reticence. It is also important to acknowledge that the social workers were not offered any additional time or resource to support recruitment and

whilst they were all supportive of the project in principle and invaluable to recruitment, this support was an additional ask during a very difficult and challenging period for the NHS.

#### *5.3.3.6 COVID-19 lock-down – barrier or facilitator?*

An additional barrier to the qualitative research, which impacted on everyone involved in the study, was that of the COVID-19 pandemic, and the society wide restrictions implemented by the UK Government in response to it. At the most obvious level, social distancing restrictions and the first national lockdown in Spring 2020, legally precluded the interviews being conducted as anticipated. An NHS Research Ethics Committee amendment to allow interviews to proceed remotely was granted, but this nonetheless created a delay of several months. Even once the NHS Research Ethics Committee amendment was in place, allowing remote interviews, the ongoing restrictions continued to compromise the usual activities and processes which would enhance recruitment. For example, I had hoped to display posters and leaflets in communal areas of the hospitals through which I was recruiting to be as sure as possible that information about the study would reach eligible people, however, as no-one was visiting, this strategy was rendered futile. This had the concurrent effect of increasing dependence on staff to enable recruitment. At the same time, clinicians were working on reduced staffing levels to reduce risks to each other and to the patients, making any requests for their support with research more burdensome. The previously routine informal discussions and enquiry with clinical staff on site concurrently became impossible. Even beyond the lockdown(s), pressures on clinical staff remained high, and in recent months the social work team at the main site for recruitment has continued to be strained by staff self-isolation, sickness, and subsequent requirements for staff to provide cross cover. Simultaneously, patients struggling after months of restrictions were described by social workers as needing greater input, further reducing capacity among clinical staff to support additional research activities. Although I was able to discuss the research project with staff and some parent patients prior to lockdown, most discussion about the research was virtual, or even more detached, by email. This prevented parent patients

being able to get a sense of the researcher that their son or daughter would speak to or to establish rapport. The launch of the project at the second site was done entirely by virtual presentation and follow up, and technical challenges on the site on the day of the initial presentation further undermined efforts to develop relationships. Despite strong support from team leader colleagues there, no participants were recruited from the second site. Given that face to face recruiting and the strength of the relationship between recruiter and the recruitment site staff were cited as key facilitators to facilitating participation in trials these barriers are likely to be important (Huntington et al., 2017).

#### *5.3.3.7 Summarising the recruitment issues*

It is evident therefore that several barriers existed in recruiting to this research project, some of which are inherent to all research, given that most research participation requires a high level of altruism, and some related to the nature of the project and the pool of participants more specifically. These factors were further affected by the pandemic, which removed many of the facilitative processes for recruitment and the possibility of any planned face to face interviews. A long delay then ensued as the research methods were adjusted to allow remote interviewing and the project was resubmitted to the research ethics committee. Those people who agreed to be interviewed over Teams/Zoom were not apparently deterred by the remote interviewing, indeed, one of the participants had hoped to attend a face-to-face interview pre-COVID but had been unable to do so due to practical issues around travel but was able to join the rearranged remote interview without issue. It may be that for this participant and maybe others, the possibility of joining and participating in the interview remotely, was an enabling factor in them taking part in the research, rather than a barrier. It certainly seems likely that for the two of the participants who lived outside the South Wales area, the remote interviewing options may have been a benefit and not a barrier. The increased familiarity for people of remote working, and communicating online more generally, after the COVID pandemic, may increase scope for some people who would otherwise have struggled to participate in research interviews

to do so in the future. Of course, some new barriers arose from this change in modality for my project, including that internet connectivity was lost during one interview and two interviews were conducted with audio only. However, no participant indicated any concern or distress by these occurrences. It is quite possible then, on balance, that the challenges of COVID, and the delays around applying for the NHS Research Ethics Committee amendment, may have had a positive outcome in the end.

## **5.4 Strengths and limitations**

### **5.4.1 Strengths**

The most notable strength of this thesis is that it examined, for the first time in the research literature, the experience of the offspring of secure hospital patients. Although previously published research contains much material of relevance, none brings together the totality of these offspring's experiences and particularly the number and range of Adverse Childhood Experiences that they face. The review of systematic reviews regarding offspring outcomes in the context of major parental psychiatric disorder was systematic in its approach and involved quality assessment of short-listed papers. The 9-year cohort study was the first period prevalence study to focus on patients as parents and their offspring. The qualitative work was the first time that offspring of secure hospital patients had been asked, in a research context, to describe their experience, and it has provided an important first exploration of their experience.

### **5.4.2 Limitations**

Inevitably there were limitations to each area of research incorporated in this thesis. Except for the review of systematic reviews on offspring outcomes in the context of parental major psychiatric disorder, the reviewing work was of a scoping nature. The

other topics reviewed would require full systematic literature reviewing to ensure a comprehensive picture of findings, although the foundations for this in terms of search terms and protocols having been drafted are in place. It is also worth noting that whilst the main facets of offspring experience were explored in the literature reviewing work, this meant that some decisions had to be made about what areas of the literature would best reflect these. There are almost certainly other relevant areas of research that it was beyond the scope of my work to additionally review, such as parent-child separation in the context of parental divorce. The other limitation related to reviewing the literature for systematic reviews is that some areas – such as offspring resilience - may have been addressed in single studies, but not necessarily come through strongly in the systematic review literature as yet. The period prevalence study in chapter 3 was confined to one regional secure hospital and may not represent dense urban and ethnically diverse populations. Although the findings from the cohort study in relation to the women detained were novel and indicated an important potential vulnerability in the offspring of mothers, the numbers were very small.

The qualitative study in chapter 4 was limited by the pandemic in terms of delays, and recruitment was additionally challenged by a number of barriers, as discussed. Therefore, not only did the grounded theory study not provide saturated data, but the sample may also have been ‘super-self-selected’. It was striking that the actual participants seemed to have coped very well in the longer term, raising the possibility that only those who had been able to resolve their sense of stigma and core concern of chaos and confusion felt able to take part. Getting over the potential barrier to participation created by a sense of stigma is likely to be one of the next big challenges to taking this work forward, hence the discussion emphasis on stigma.

## **5.5 Recommendations**

Considering the findings from the research in this thesis several recommendations for further work can be made. I will outline these in relation to each of the chapters of the

thesis from chapters 2 to 4 inclusive, considering first, recommendations for further research and second, recommendations for policy makers/practitioners.

### ***5.5.1 Recommendations for future research***

The literature reviewing work detailed in chapter 2 was important in enabling me to understand whether exploring the experience of the offspring of patients detained in secure psychiatric hospitals was an important research task and the results supported pursuing this avenue of enquiry. I was able to examine the literature on a key facet of offspring experience, that of having a parent with a major psychiatric disorder, and I did so in some detail, narratively synthesising quality assessed systematic reviews. For the other two broad areas - parental risk to others, including parental incarceration, and child-parent separation – I was able to perform and later update scoping searches of the relevant literature. However, given that the updated searches revealed more recent relevant research further work, it would be beneficial to conduct further systematic literature reviews. In relation to the specific facet of work on offspring outcomes when a parent is imprisoned, given it is 10 years since the Murray et al., (2012) review was published, an update would be worthwhile. It would also be helpful to include qualitative work in any such review given the paucity of narrative from the offspring themselves. Such work would complement the literature reviewing work on offspring experience of stigma when a parent is imprisoned, which is underway (Kalebic et al., 2021).

In relation to the research findings from the quantitative cohort study described in chapter 3, there are a number of avenues of enquiry which could be taken forwards. Given the increased prevalence of parenthood identified in the 9-year cohort, and the possibility that regional differences might account for this, it would provide useful context to establish a UK-wide prevalence study or, at least, examine a similar period prevalence of parenthood in a secure hospital or hospital(s), which encompassed a denser urban catchment area and a more ethnically diverse population, to enable commentary on the representativeness of my finding.

With regards to hearing directly from the offspring of these hospitalised parents, the first task would be to extend the study duration beyond what was possible for the purpose of the PhD to seek further interviews, to bring the data to saturation. This would enable this work to be written up for peer reviewed publication. All participants in my qualitative work agreed to be contacted should further related research opportunities arise.

### ***5.5.2 Recommendations for policy and practice***

The evidence of the benefits of Family Focussed Practice were presented in chapter 4 as well as some of the barriers to this being realised. In the context of the evidence of stigma exerting an additional challenge in the lives of these offspring, actively practising Family Focussed Practice appears to have scope for a very real and positive impact on the lives of offspring. Given the incidental observation in chapter 3 that the patients were often in contact with other family members of dependent age, such as nieces, nephews, and grandchildren, Family Focussed Practice could have beneficial effects beyond the offspring themselves. Direct work with the family could increase dialogue within the families of patients, and improve mental health literacy, thus beginning to tackle a likely important perpetuating factor in stigma. Offspring being included in open discussion around the experience of a parent being in prison was shown to enhance child coping, thus indicating a further potential benefit to this work which may extend to my population of interest (Thulstrup and Karlsson, 2017).

There might be advantages to there being a dedicated practitioner for Family Focussed Practice as well as, and as part of, ensuring that there is a culture for this embedded within every secure hospital. A dedicated practitioner may assist with removing barriers within healthcare professionals' own minds and facilitate acceptance of Family Focussed Practice as a role for everyone. If even a small amount of time was able to be dedicated to direct assessment and, if indicated, support and/or intervention for the offspring, this could enable more focus on the possibility of inter-agency working, and perhaps especially with schools given the Whole School Approach and emphasis on pupil well-being in Wales. However, this would require information sharing across agencies, which



may raise important issues regarding parent-patient confidentiality if schools were not otherwise aware of the child's experience. It is also important to remember that Family Focussed Practice should also be available to families in which there are also, or indeed only, adult aged offspring. None of this would be straightforward as special care has to be taken with information sharing between agencies, but forensic mental health services already have extensive experience of this through Multi-Agency Public Protection Arrangements (MAPPA) processes, which are applicable to almost all secure hospital patients, and lessons from that might be transferable.

The finding in chapter 3 that offspring of mothers detained in secure hospitals were more likely to have been a victim or witness in the index offence and yet the mother more likely to have been the primary carer to the child both over the child's lifespan, and in the year prior to the parent's admission, highlights this group as potentially being particularly vulnerable. Given that the number of secure hospital beds for women in England and Wales is much smaller than for men (Somers and Bartlett, 2014), the number of children who would require assessment and possible input would be relatively small. This may offer scope for this subgroup to be offered assessment and, if required, intervention. It would of course be important for any such service development to provide parity of provision with that offered to offspring of fathers detained in secure settings, and this would require further careful consideration.

## **5.6 Conclusions**

With this thesis I have sought to remedy a gap in the research literature by exploring the experience of the offspring of parents who are detained in secure psychiatric settings. I used a mixed methods approach which included literature reviewing, quantitative survey work and a qualitative interview project with adult aged offspring. The results from each method employed contributed to an overarching message of the importance of identifying, and where necessary, supporting offspring who have a parent in a secure psychiatric hospital. Through literature reviewing work I synthesised already published

work on the three main facets of offspring experience. The outcomes for offspring were mostly of an increased risk of problems, including developing psychiatric disorder and/or internalising and externalising problems, as well as some evidence of cognitive and social problems. This culminates to demonstrate the likely presence of need in the offspring of secure hospital patients. In the quantitative survey work, I indicated that higher numbers of offspring in England and Wales are affected by parental secure psychiatric hospital admission than previously thought. This shows that the size of the population affected by the needs indicated as being likely to be relevant in the literature reviewing work may be larger than previously evidenced. I also discovered some risks to the offspring, including the risk of having been a witness or victim of the index offence, and that the offspring of mothers detained in hospital are perhaps particularly vulnerable. This finding was in keeping with the overall theme from the reviewing work of increased problems for offspring but added detail as to the specific risks which this population may face. The quantitative work in chapter 3 also highlighted a pattern of almost half of the offspring aged under 18-years-old who had been living with their parent prior to admission having lost all contact with the parent in the year post admission, whilst all adult aged offspring who had been living with their parent-patient, retained some sort of contact in the year after the parental admission. This is likely to represent a complex multifaceted situation, including child protection issues for the under 18-year-olds, and perhaps some relational factors in the parent-offspring dynamics for the adult aged offspring who remained at home post 18-years old, which may have contributed to their continued contact in the year after the parent's admission. The likely complexities and the questions raised by this finding further substantiated the next step in the mixed methods design, which was to speak to offspring who had experienced having a parent in a secure setting and who could provide detail about what happened from their perspective. In relation to this what still warrants further exploration are the processes around the decision making for the complete break in contact for the under 18-year-olds. Interviews or focus groups with social workers and/or other clinicians may help researchers to understand the processes.

The qualitative work involved speaking with adult aged offspring for the first time in a research context. Recruitment to this project proved challenging and barriers were

subsequently explored. Some of the decision making by healthcare professionals around whether offspring were 'able' to decide to participate perhaps mirrored some of the thinking which resulted in such a high proportion of younger offspring not being facilitated to have any contact at all with their parent in the year after admission – not even writing letters – and even when they had been living together before. Despite the challenges in recruitment, the four participants who took part provided detailed, thoughtful accounts. Given the previous absence of first-hand reports of offspring experience in this situation these are incredibly important and enabled the offspring core concern of 'chaos and confusion' to emerge, together with a model indicating how a move to resolution occurred with offspring finding stability, security and autonomy. The offspring accounts in both their responses to the open-ended interview question, which culminated in the model of understanding, and their answers to the semi-structured interview questions were convergent with the results of the literature reviewing and the quantitative survey. That the offspring core concern was one of 'chaos and confusion' is consistent with the literature reviewing, which pointed towards the likelihood of increased problems for offspring when a parent has a psychiatric disorder, but added detail around what these were for offspring in the specific situation of having a parent in a secure psychiatric hospital. The participants' retrospective recollections of how they experienced the separation from their parent when they were in the secure hospital added rich information to the quantitative data around the separation and loss of contact. Notably, all but one of the participants who spoke to me had experienced complete loss of contact with their parent as a dependent aged child but this break in contact was not necessarily recalled as a negative experience. However, for the participants, making sense of the parent's behaviour prior to being detained in the secure hospital was a challenge and may be one which could have been in part at least ameliorated by contact with the parent, supported by health and/or social care professionals.

Stigma was a theme which although not examined in depth in the literature review, and not explicitly named by any of the adult participants in their response to the open interview question, was nonetheless present in every aspect of my work and was, therefore, described in some detail in chapter 4 and discussed earlier in this chapter. I

also discussed in this chapter, some of the risks to the offspring relating to their experience of having a secure hospital patient-parent. The risks to offspring which emerged during the research were wide ranging and within this discussion point I focussed on three areas: the risk to the offspring of developing psychiatric disorder(s); the risk of them being physical harmed; and the risk of them being emotionally abused and/or neglected. There was evidence of increased risk in all these areas of adversity, however, there was also scope to begin to think about ways in which risk could be mitigated through recent developments, including the opening last year (2021) of an inpatient psychiatric hospital in Wales for mothers and babies in the perinatal period. There is also scope to mitigate risks for older children, in the launch of the new school curriculum in Wales, which has a commitment to developing healthy individuals and a greater focus on mental well-being. Evidence also continues to grow emphasising the benefits of a Family Focussed Practice approach. The evidence from this thesis would support the idea that healthcare linking up with relevant agencies which support children, to ensure that families have the mental health literacy to understand and support each other, as well as support from professionals where needed, has potential to enhance resilience and coping in these families. This is of course, providing that protocols for appropriate protections of confidentiality, and other individual rights are in place. Such measures may assist the parent-patient in their recovery as well as helping the offspring.

## References:

### A

Abel, K.M., Hope, H., Swift, E., Parisi, R., Ashcroft, D.M., Kosidou, K., Osam, C.S., Dalman, C. and Pierce, M. (2019). Prevalence of maternal mental illness among children and adolescents in the UK between 2005 and 2017: a national retrospective cohort analysis. *The Lancet Public Health*, 4(6), pp.e291–e300. Available at: [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(19\)30059-3/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(19)30059-3/fulltext) (Accessed on: 20 March 2021).

Abela, J. R., Skitch, S. A., Auerbach, R. P., & Adams, P. (2005). The impact of parental borderline personality disorder on vulnerability to depression in children of affectively ill parents. *Journal of personality disorders*, 19(1), pp. 68–83. Available at: <https://doi.org/10.1521/pedi.19.1.68.62177> (Accessed on: 27 April 2022).

Achenbach, T. M., and Rescorla, L. A. (2001). *Manual for the ASEBA school-age forms & profiles: an integrated system of multi-informant assessment*. Burlington: University of Vermont, Research Center for Children, Youth & Families.

Adams, A. (2012). *Offender patients and their children: social worker perspectives of parenting needs*. BSc Dissertation. Cardiff: Cardiff University.

Adderley, H., Wittkowski, A., Calam, R. and Gregg, L. (2020). Adult mental health practitioner beliefs about psychosis, parenting, and the role of the practitioner: A Q methodological investigation. *Psychology and Psychotherapy: Theory, Research and Practice*, 93(4), pp. 657-673.

Agerbo, E., Nordentoft, M., and Mortensen, P. B. (2002). Familial, psychiatric, and socioeconomic risk factors for suicide in young people: nested case-control study. *BMJ (Clinical research ed.)*, 325(7355), 74. Available at: <https://doi.org/10.1136/bmj.325.7355.74> (Accessed on: 28 April 2022).

Ahmedani, B. K. (2011). Mental Health Stigma: Society, Individuals and the Profession. *Journal of Social Work Values and Ethics*, 8(2), pp.4-1 – 4-16. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3248273/pdf/nihms342711.pdf> (Accessed on: 20 May 2022).

Aktar, E., Qu, J., Lawrence, P. J., Tollenaar, M. S., Elzinga, B. M. and Bögels, S. M. (2019). Fetal and Infant Outcomes in the Offspring of Parents With Perinatal Mental Disorders: Earliest Influences. *Frontiers in Psychiatry*, 10 (391). Available at: <https://doi.org/10.3389/fpsyt.2019.00391> (Accessed on: 20 May 2022).

- Alastalo, H., Raikkonen, K., Pesonen, A. K., Osmond, C., Barker, D. J., Kajantie, E., Heinonen, K., Forsen, T. J., & Eriksson, J. G. (2009). Cardiovascular health of Finnish war evacuees 60 years later. *Annals of medicine*, 41(1), pp. 66–72. Available at: <https://doi.org/10.1080/07853890802301983> (Accessed on: 29 April 2022).
- Amato, P.R. and Keith, B. (1991). Parental divorce and the well-being of children: A meta-analysis. *Psychological Bulletin*, 110(1), pp.26–46.
- An, R., Cao, L., Wang, J., Yang, Q., Yang, Y. and Yin, X. (2019). Impact of Parental Incarceration on Body Weight Status of Children and Young Adults: A Systematic Review and Meta-analysis. *American Journal of Health Behavior*, 43(4), pp.824–837.
- Anda, R.F., Felitti, V.J., Bremner, J.D., Walker, J.D., Whitfield, Ch., Perry, B.D., Dube, Sh.R. and Giles, W.H. (2006). The enduring effects of abuse and related adverse experiences in childhood. A convergence of evidence from neurobiology and epidemiology. *European Archives of Psychiatry and Clinical Neuroscience*, 256(3), pp.174–186. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3232061/>. (Accessed on: 02 May 2022).
- Andrews, D. A., Bonta, J. and Wormith, J. S. (2011). The Risk-Need-Responsivity (RNR) Model. *Criminal Justice and Behavior*, 38(7), pp.735–755. Available at: <https://journals.sagepub.com/doi/abs/10.1177/0093854811406356> (Accessed on: 20 May 2022).
- Argent, S. E., Riddleston, L., Warr, J., Tippetts, H., Meredith, Z. and Taylor, P. J. (2017). A period prevalence study of being a parent in a secure psychiatric hospital and a description of the parents, the children and the impact of admission on parent-child contact. *Criminal Behaviour and Mental Health*, 28(1), pp.85–99.
- Argent, S. E., Kalebic, N., Rice, F. and Taylor, P. (2020). Offspring outcomes when a parent experiences one or more major psychiatric disorder(s): a clinical review. *Evidence Based Mental Health*, 23(3), pp.113–121.
- Asmussen, K., Fischer, F. Drayton, E. and McBride, T. (2020). *Adverse childhood experiences, what we know, what we don't know, and what should happen next*. London: Early Intervention Foundation. Available at: <https://www.eif.org.uk/report/adverse-childhood-experiences-what-we-know-what-we-dont-know-and-what-should-happen-next> (Accessed on 07 May 2022).
- Atuel, H.R., Gilreath, T.D., Astor, R.A., Cederbaum, J.A., Benbenishty, R. and Pineda, D. (2014). Perceived discriminatory bullying among military-connected students attending public schools. *Military Behavioral Health*, 2(2), pp.147-152.
- Austin, A.E., Lesak, A.M. and Shanahan, M.E. (2020). Risk and Protective Factors for Child Maltreatment: A Review. *Current Epidemiology Reports*, 7(4), pp.334–342.

## B

Baldwin, J.R., Reuben, A., Newbury, J.B. and Danese, A. (2019). Agreement Between Prospective and Retrospective Measures of Childhood Maltreatment. *JAMA Psychiatry*, 76(6), p.584.

Barnes, V.A., Davis, H. and Treiber, F.A. (2007). Perceived Stress, Heart Rate, and Blood Pressure among Adolescents with Family Members Deployed in Operation Iraqi Freedom. *Military Medicine*, 172(1), pp.40–43.

Barnow, S., Spitzer, C., Grabe, H., Kessler, C. and Freyberger, H., (2006). Individual Characteristics, Familial Experience, and Psychopathology in Children of Mothers With Borderline Personality Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, 45(8), pp.965-972.

Barnow, S., Aldinger, M., Arens, E., Ulrich, I., Spitzer, C., Grabe, H. and Stopsack, M. (2013). Maternal Transmission of Borderline Personality Disorder Symptoms in the Community-Based Greifswald Family Study. *Journal of Personality Disorders*, 27(6), pp.806-819.

Beardslee, W.R., Bemporad, J., Keller, M.B., Klerman, G.L. (1983). Children of parents with major affective disorder: a review. *Am J Psychiatry*, 140, pp. 825-832.

Bee, P., Bower, P., Byford, S., Churchill, R., Calam, R., Stallard, P., Prymachuk, S., Berzins, K., Cary, M., Wan, M. and Abel, K. (2014). The clinical effectiveness, cost-effectiveness and acceptability of community-based interventions aimed at improving or maintaining quality of life in children of parents with serious mental illness: a systematic review. *Health Technology Assessment*, 18(8), pp. 1-249.

Bella, T., Goldstein, T., Axelson, D., Obreja, M., Monk, K., Hickey, M.B., Goldstein, B., Brent, D., Diler, R.S., Kupfer, D., Sakolsky, D. and Birmaher, B. (2011). Psychosocial Functioning in Offspring of Parents with Bipolar Disorder. *Journal of affective disorders*, 133(1-2), pp.204–211. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3131462/> (Accessed on: 24 May 2020).

Bellis, M.A., Hughes, K., Leckenby, N., Perkins, C. and Lowey, H. (2014). National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Medicine*, 12(1). Available at: <https://bmcmmedicine.biomedcentral.com/articles/10.1186/1741-7015-12-72> (Accessed on: 16 May 2022).

Bellis, M. A., Ashton, K., Hughes, K., Ford, K., Bishop, J., & Paranjothy, S. (2015). *Welsh adverse childhood experience (ACE). Adverse childhood experiences and their impact on health-harming behaviours in the Welsh adult population*. Cardiff: Public Health Wales and John Moore's University. <https://phw.nhs.wales/files/aces/aces-and-their-impact-on-health-harming-behaviours-in-the-welsh-adult-population-pdf/> (Accessed on: 07 May 2022).

Bello-Utu, C.F. and DeSocio, J.E. (2015). Military Deployment and Reintegration: A Systematic Review of Child Coping. *Journal of Child and Adolescent Psychiatric Nursing*, 28(1), pp.23–34.

Bergink, V., Lambregtse-van den Berg, M.P., Koorengevel, K.M., Kupka, R. and Kushner, S.A. (2011). First-Onset Psychosis Occurring in the Postpartum Period. *The Journal of Clinical Psychiatry*, 72(11), pp.1531–1537.

Bertino, M., Connell, G. and Lewis, A., (2012). The association between parental personality patterns and internalising and externalising behaviour problems in children and adolescents. *Clinical Psychologist*, 16(3), pp.110-117.

Birmaher, B., Axelson, D., Goldstein, B., Monk, K., Kalas, C., Obreja, M., Hickey, M.B., Iyengar, S., Brent, D., Shamseddeen, W., Diler, R. and Kupfer, D. (2010). Psychiatric Disorders in Preschool Offspring of Parents With Bipolar Disorder: The Pittsburgh Bipolar Offspring Study (BIOS). *American Journal of Psychiatry*, 167(3), pp.321–330.

Blake-Holmes, K. (2020). Young adult carers: making choices and managing relationships with a parent with a mental illness, *Advances in Mental Health and Intellectual Disabilities*, 18(3), pp. 230–240. Available at: <https://doi.org/10.1080/18387357.2019.163669> (Accessed on: 01 May 2022).

Blitz, L. V., Kida, L., Gresham, M. and Bronstein, L. R. (2013). Prevention through collaboration: Family engagement with rural schools and families living in poverty. *Families in Society*, 94(3), pp. 157–165.

Boch, S.J. and Ford, J.L. (2018). Health Outcomes of Youth in the United States Exposed to Parental Incarceration. *Journal of Forensic Nursing*, 14(2), pp.61–71.

Bonevski, B., Randell, M., Paul, C., Chapman, K., Twyman, L., Bryant, J., Brozek, I. and Hughes, C., (2014). Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology*, 14(1).

Boursnell, M. (2011). Parents With Mental Illness: The Cycle of Intergenerational Mental Illness. *Children Australia*, 36(1), pp.26–35.

Bowlby, J. (1973). *Attachment and loss. Vol. 2, Separation. Anger and anxiety*. London: Pimlico.



Bowlby, J. (1988). *A secure base: Parent-child attachment and healthy human development*. New York: Basic Books.

Breslau, J., Miller, E., Jin, R., Sampson, N., Alonso, J., Andrade, L., Bromet, E., de Girolamo, G., Demyttenaere, K., Fayyad, J., Fukao, A., Gălăon, M., Gureje, O., He, Y., Hinkov, H., Hu, C., Kovess-Masfety, V., Matschinger, H., Medina-Mora, M., Ormel, J., Posada-Villa, J., Sagar, R., Scott, K. and Kessler, R. (2011). A multinational study of mental disorders, marriage, and divorce. *Acta Psychiatrica Scandinavica*, 124(6), pp.474-486.

Brockington, I.F., Cernik, K., Schofield, E., Downing, A., Francis, A., and Keelan, C. (1981) Puerperal psychosis: phenomena and diagnosis. *Arch Gen Psychiatry*, 38(7), pp.829–833.

Brown, G., Harris, T., and Copeland, J. (1977). Depression and Loss. *British Journal of Psychiatry*, 130, pp.1-18.

Brown, G., Marshall, M., Bower, P., Woodham, A. and Waheed, W., 2014. Barriers to recruiting ethnic minorities to mental health research: a systematic review. *International Journal of Methods in Psychiatric Research*, 23(1), pp.36-48.

Bunting, L. (2004). Parenting Programmes: The Best Available Evidence. *Child Care in Practice*, 10(4), pp.327–343.

Butler Report. (1975). *Report of the Committee on Mentally Abnormal Offenders*, (CMND 6244). London: HMSO.

## C

Campbell, S.B., Morgan-Lopez, A.A., Cox, M.J. and McLoyd, V.C. (2009). A latent class analysis of maternal depressive symptoms over 12 years and offspring adjustment in adolescence. *Journal of Abnormal Psychology*, 118(3), pp.479–493.

Card, N.A., Bosch, L., Casper, D.M., Wiggs, C.B., Hawkins, S.A., Schlomer, G.L. and Borden, L.M. (2011). A meta-analytic review of internalizing, externalizing, and academic adjustment among children of deployed military service members. *Journal of Family Psychology*, 25(4), pp.508–520.

Care Act (2014). c. 23 Statute Law Database. Available at: <https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted> (Accessed on: 07 May 2022).

Centre for Reviews & Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in healthcare*. York: University of York NHS Centre for Reviews & Dissemination.

- Chandra, P.S., Bhargavaraman, R.P., Raghunandan, V.N.G.P. and Shaligram, D. (2006). Delusions related to infant and their association with mother-infant interactions in postpartum psychotic disorders. *Archives of Women's Mental Health*, 9(5), pp.285–288. Available at: <https://pubmed.ncbi.nlm.nih.gov/16937315/> (Accessed 5 Nov. 2020).
- Chang, J.J., Halpern, C.T. and Kaufman, J.S. (2007). Maternal depressive symptoms, father's involvement, and the trajectories of child problem behaviors in a US national sample. *Archives of Pediatrics & Adolescent Medicine*, 161(7), pp.697–703. Available at: <https://pubmed.ncbi.nlm.nih.gov/17606834/> (Accessed on: 15 Jun. 2020).
- Chao, O. and Kuti, G. (2009). Supporting children of forensic in-patients: whose role is it? *Psychiatric Bulletin*, 33(2), pp.55–57.
- Chapman, D., Whitfield, C., Felitti, V., Dube, S., Edwards, V. and Anda, R., (2004). Adverse childhood experiences and the risk of depressive disorders in adulthood. *Journal of Affective Disorders*, 82(2), pp.217-225.
- Charmaz, K. (2006). *Constructing Grounded Theory: a Practical Guide Through Qualitative Analysis*. Thousand Oaks, CA: Sage.
- Charmaz, K. (2014). *Constructing Grounded Theory (Introducing Qualitative Methods series) 2<sup>nd</sup> Edition*. Thousand Oaks, CA: Sage.
- Cheng, H., Huang, Y., Liu, Z. and Liu, B., (2011). Associations linking parenting styles and offspring personality disorder are moderated by parental personality disorder, evidence from China. *Psychiatry Research*, 189(1), pp.105-109.
- Cheng, C.-C. J., Yen, W.-J., Chang, W.-T., Wu, K.C.-C., Ko, M.-C. and Li, C.-Y. (2014). Risk of adolescent offspring's completed suicide increases with prior history of their same-sex parents' death by suicide. *Psychological Medicine*, 44(9), pp.1845–1854.
- Children, Schools and Families Act (2010). c. 25 Statute Law Database. Available at: <https://www.legislation.gov.uk/ukpga/2010/26/contents> (Accessed on: 07 May 2022).
- Coid, J., Hickey, N., Kahtan, N., Zhang, T. and Yang, M. (2007). Patients discharged from medium secure forensic psychiatry services: reconvictions and risk factors. *British Journal of Psychiatry*, 190(03), pp.223–229.
- Collishaw, S., Hammerton, G., Mahedy, L., Sellers, R., Owen, M.J., Craddock, N., Thapar, A.K., Harold, G.T., Rice, F. and Thapar, A. (2016). Mental health resilience in the adolescent offspring of parents with depression: a prospective longitudinal study. *The Lancet Psychiatry*, 3(1), pp.49–57.
- Connell, A.M. and Goodman, S.H. (2002). The association between psychopathology in fathers versus mothers and children's internalizing and externalizing behavior problems: A meta-analysis. *Psychological Bulletin*, 128(5), pp.746–773.

Conway, C., Hammen, C. and Brennan, P., (2015). Adolescent Precursors of Adult Borderline Personality Pathology in a High-Risk Community Sample. *Journal of Personality Disorders*, 29(3), pp.316-333.

Cooklin, A. (2010). Living upside down: being a young carer of a parent with mental illness. *Advances in Psychiatric Treatment*, 16(2), pp.141–146. Available at: <https://www.cambridge.org/core/journals/advances-in-psychiatric-treatment/article/living-upside-down-being-a-young-carer-of-a-parent-with-mental-illness/E016BA154BB196DABA377DE352E62E00#>

Cooklin, A. (2013). Promoting children's resilience to parental mental illness: Engaging the child's thinking. *Advances in Psychiatric Treatment*, 19(3), pp. 229-240.

Corapci, F., Smith, J. and Lozoff, B. (2006). The Role of Verbal Competence and Multiple Risk on the Internalizing Behavior Problems of Costa Rican Youth. *Annals of the New York Academy of Sciences*, 1094(1), pp.278–281.

Corrigan, P. W., and Kleinlein, P. (2005). 'Impact of Mental Illness Stigma'. In: P. W. Corrigan (ed.) *On the Stigma of Mental illness: Practical Strategies for Research and Social Change* Washington, DC: American Psychological Association, pp. 186-199. Available at: <http://dx.doi.org/10.1037/10887-001> (Accessed on: 20 May 2022).

Cortes, R.C., Fleming, C.B., Catalano, R.F. and Brown, E.C. (2006). Gender Differences in the Association between Maternal Depressed Mood and Child Depressive Phenomena from Grade 3 through Grade 10. *Journal of Youth and Adolescence*, 35(5), pp.810–821.

Cowling, V. (Ed.). (2004). *Children of parents with mental illness 2: Personal and clinical perspectives*. Melbourne: ACER Press.

Creech, S.K., Hadley, W. and Borsari, B. (2014). The impact of military deployment and reintegration on children and parenting: A systematic review. *Professional Psychology: Research and Practice*, 45(6), pp.452–464. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4383395/>. (Accessed on 29 April 2022).

Creeley and Denton, (2019). Use of Prescribed Psychotropics during Pregnancy: A Systematic Review of Pregnancy, Neonatal, and Childhood Outcomes. *Brain Sciences*, 9(9), p.235.

Cronholm, P.F., Forke, C.M., Wade, R., Bair-Merritt, M.H., Davis, M., Harkins-Schwarz, M., Pachter, L.M. and Fein, J.A. (2015). Adverse Childhood Experiences: Expanding the Concept of Adversity. *American Journal of Preventive Medicine*, 49(3), pp.354–361.

Cummings, E., Keller, P.S. and Davies, P.T. (2005). Towards a family process model of maternal and paternal depressive symptoms: exploring multiple relations with child and family functioning. *Journal of Child Psychology and Psychiatry*, 46(5), pp.479–489.

Cunitz, K., Dölitzsch, C., Kösters, M., Willmund, G.-D., Zimmermann, P., Bühler, A.H., Fegert, J.M., Ziegenhain, U. and Kölch, M. (2019). Parental military deployment as risk factor for children's mental health: a meta-analytical review. *Child and Adolescent Psychiatry and Mental Health*, 13(26). Available at: <https://capmh.biomedcentral.com/track/pdf/10.1186/s13034-019-0287-y.pdf> (Accessed on: 20 May 2022).

## D

Dahl, S.K., Larsen, J.T., Petersen, L., Ubbesen, M.B., Mortensen, P.B., Munk-Olsen, T. and Musliner, K.L. (2017). Early adversity and risk for moderate to severe unipolar depressive disorder in adolescence and adulthood: A register-based study of 978,647 individuals. *Journal of Affective Disorders*, 214, pp.122–129.

Danese, A., Widom, C.S. (2020). Objective and subjective experiences of child maltreatment and their relationships with psychopathology. *Nat Hum Behav*, 4, pp. 811–818. Available at: <https://doi.org/10.1038/s41562-020-0880-3> (Accessed on 20 May 2022).

Darlington, Y. and Feeney, J.A. (2009). Clients' and Professionals' Experiences of Traversing Mental Health and Child Protection Systems: Implications for Practice. *Families in Society: The Journal of Contemporary Social Services*, 90(4), pp.382–389.

Dazzi, T., Gribble, R., Wessely, S., & Fear, N. (2014). Does asking about suicide and related behaviours induce suicidal ideation? What is the evidence? *Psychological Medicine*, 44(16), pp. 3361–3363.

DelBello, M.P. and Geller, B. (2001). Review of studies of child and adolescent offspring of bipolar parents. *Bipolar Disord*, 6, pp.325–34.

Devaney, J., Davidson, G., Grant, A. and Lagdon, S. (2020). Supporting parents with mental illness and their children – developments in family focused practice in the United Kingdom and Ireland. *Advances in Mental Health*, 18(3), pp.197–201.

De Rosbo-Davies, C., Laletas, S. and Round, P. (2021). Daughters' experiences of maternal bereavement during adolescence: A scoping review. *Death Studies*, pp.1–11.

De Vogel, V., Stam, J., Bouman, Y.H.A., Ter Horst, P. and Lancel, M. (2015). Violent women: a multicentre study into gender differences in forensic psychiatric patients. *The Journal of Forensic Psychiatry & Psychology*, 27(2), pp.145–168.

Dick, G. (2005). Witnessing marital violence as children: men's perceptions of their fathers. *Journal of Social Service Research*, 32(2), pp. 1– 24.

Dietz, L.J., Birmaher, B., Williamson, D.E., Silk, J.S., Dahl, R.E., Axelson, D.A., Ehmann, M. and Ryan, N.D. (2008). Mother-Child Interactions in Depressed Children and Children at High Risk and Low Risk for Future Depression. *Journal of the American Academy of Child & Adolescent Psychiatry*, 47(5), pp.574–582.

Dobener, L.-M., Fahrner, J., Purtscheller, D., Bauer, A., Paul, J.L. and Christiansen, H. (2022). How Do Children of Parents With Mental Illness Experience Stigma? A Systematic Mixed Studies Review. *Frontiers in Psychiatry*, 13.

Dolman, C., Jones, I. and Howard, L.M. (2013). Pre-conception to parenting: a systematic review and meta-synthesis of the qualitative literature on motherhood for women with severe mental illness. *Archives of Women's Mental Health*, 16(3), pp.173–196.

Donovan, B. M., Spracklen, C. N., Schweizer, M. L., Ryckman, K. K., & Saftlas, A. F. (2016). Intimate partner violence during pregnancy and the risk for adverse infant outcomes: a systematic review and meta-analysis. *BJOG : an international journal of obstetrics and gynaecology*, 123(8), pp. 1289–1299. Available at: <https://doi.org/10.1111/1471-0528.13928> (Accessed on: 29 April 2022).

Downey, G and Coyne, J.C. (1990). Children of depressed parents: an integrative review. *Psychol bull*, 108, pp. 50-76.

Doyle, M., Coid, J., Archer-Power, L., Dewa, L., Hunter-Didrichsen, A., Stevenson, R., Wainwright, V., Kallis, C., Ullrich, S. and Shaw, J. (2014) Discharges to prison from medium secure psychiatric units in England and Wales, *British Journal of Psychiatry*. Cambridge University Press, 205(3), pp. 177–182. Available at: doi: 10.1192/bjp.bp.113.136622

Dunn, B. (1993). Growing up with a psychotic mother: A retrospective study. *American Journal of Orthopsychiatry*, 63(2), pp.177–189.

Dunn, A., Startup, H. and Cartwright-Hatton, S. (2021). Adult mental health service engagement with patients who are parents: Evidence from 15 English mental health trusts. *British Journal of Clinical Psychology*, 61(2), pp.335–348.

## E

Earnshaw, C.H., Shaw, L., Thomas, D. and Haeney, O. (2018). A retrospective study comparing the length of admission of medium secure unit patients admitted in the three decades since 1985. *BJPsych Bulletin*, 43(4), pp.154–157.

East, L., Jackson, D. and O'Brien, L. (2006). Father absence and adolescent development: a review of the literature. *Journal of Child Health Care*, 10(4), pp.283–295.

Edleson, J.L. (1999). Children's Witnessing of Adult Domestic Violence. *Journal of Interpersonal Violence*, 14(8), pp.839–870.

Eley, T.C., McAdams, T.A., Rijdsdijk, F.V., Lichtenstein, P., Narusyte, J., Reiss, D., Spotts, E.L., Ganiban, J.M. and Neiderhiser, J.M. (2015). The Intergenerational Transmission of Anxiety: A Children-of-Twins Study. *The American journal of psychiatry*, 172(7), pp.630–7. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/25906669>.

Elgar, F.J., Mills, R.S.L., McGrath, P.J., Waschbusch, D.A. and Brownridge, D.A. (2007). Maternal and Paternal Depressive Symptoms and Child Maladjustment: The Mediating Role of Parental Behavior. *Journal of Abnormal Child Psychology*, 35(6), pp.943–955.

Ehrensaft, M. K., & Cohen, P. (2012). Contribution of family violence to the intergenerational transmission of externalizing behavior. *Prevention Science*, 13(4), pp. 370 –383. Available at: doi:10.1007/s11121-011- 0223-8 (Accessed on: 29 April 2022).

Ehrensaft, M. K., Cohen, P., Brown, J., Smailes, P., Chen, H., and Johnson, J. G. (2003). Intergenerational transmission of partner violence: a 20 year prospective study. *Journal of Consulting and Clinical Psychology*, 71, pp. 741 –753.

Evans, S.E., Davies, C. and DiLillo, D. (2008). Exposure to domestic violence: A meta-analysis of child and adolescent outcomes. *Aggression and Violent Behavior*, 13(2), pp.131–140. Available at: <http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1320&context=psychfacpub>.

Eyden, J., Winsper, C., Wolke, D., Broome, M.R. and MacCallum, F. (2016). A systematic review of the parenting and outcomes experienced by offspring of mothers with borderline personality pathology: Potential mechanisms and clinical implications. *Clinical Psychology Review*, 47, pp.85–105.

Eyre, O., Jones, R.B., Mars, B., Hammerton, G., Sellers, R., Potter, R., Thapar, A., Rice, F., Collishaw, S. and Thapar, A. (2014). Reported child awareness of parental depression. *The Psychiatric Bulletin*, 38(03), pp.122–127.

## F

Feldman, R.B., Zelkowitz, P., Weiss, M., Vogel, J., Heyman, M. and Paris, J. (1995). A comparison of the families of mothers with borderline and nonborderline personality disorders. *Comprehensive Psychiatry*, 36(2), pp.157–163.

Felitti, V.J., Anda, R.F., Nordenberg, D., Williamson, D.F., Spitz, A.M., Edwards, V., Koss, M.P. and Marks, J.S. (1998). Relationship of Childhood Abuse and Household Dysfunction to Many of the Leading Causes of Death in Adults. *American Journal of Preventive Medicine*, 14(4), pp.245–258.

Felitti, V.J., Anda, R.F. (2010). The relationship of adverse childhood experiences to adult medical disease, psychiatric disorders and sexual behavior: implications for healthcare. In: Pain C, Vermetten E, Lanius RA. (eds.), *The Impact of Early Life Trauma on Health and Disease: The Hidden Epidemic*. Cambridge: Cambridge University Press pp. 77–87.

Flynn, S.M. and Shaw, J.J. (2007). Homicide of Infants. *The Journal of Clinical Psychiatry*, 68(10), pp.1501–1509.

Fogarty, A., Wood, C.E., Giallo, R., Kaufman, J. and Hansen, M. (2019). Factors promoting emotional-behavioural resilience and adjustment in children exposed to intimate partner violence: A systematic review. *Australian Journal of Psychology*. 71(4), pp. 375-389, Available at: DOI: [10.1111/ajpy.12242](https://doi.org/10.1111/ajpy.12242) (Accessed on: 29 April 2022).

Foster, K., Maybery, D., Reupert, A., Gladstone, B., Grant, A., Ruud, T., Falkov, A., & Kowalenko, N. (2016). Family Focused Practice in Mental Health Care: An Integrative Review. *Child and Youth Services*, 37(2), pp. 129-155. Available at: <https://doi.org/10.1080/0145935X.2016.1104048>

Frias, A., Palma, C., Farriols, N., Salvador, A. (2015). Characterizing offspring of bipolar parents: a review of the literature. *Actas Esp Psiquiatr*, 44, pp. 221-34.

## G

Garber, J., Little, S., Hilsman, R. and Weaver, K.R. (1998). Family predictors of suicidal symptoms in young adolescents. *Journal of Adolescence*, 21(4), pp.445–457.

Garber, J., Clarke, G. N., Weersing, V. R., Beardslee, W. R., Brent, D. A., Gladstone, T. R., DeBar, L. L., Lynch, F. L., D'Angelo, E., Hollon, S. D., Shamseddeen, W., & Iyengar, S. (2009). Prevention of depression in at-risk adolescents: a randomized controlled trial. *JAMA*, 301(21), pp. 2215–2224. Available at: <https://doi.org/10.1001/jama.2009.788>

Gejman, P.V., Sanders, A.R. and Duan, J. (2010). The Role of Genetics in the Etiology of Schizophrenia. *Psychiatric Clinics of North America*, 33(1), pp.35–66. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2826121/>

Geulayov, G., Metcalfe, C., Heron, J., Kidger, J. and Gunnell, D. (2014). Parental Suicide Attempt and Offspring Self-Harm and Suicidal Thoughts: Results From the Avon Longitudinal Study of Parents and Children (ALSPAC) Birth Cohort. *Journal of the American Academy of Child & Adolescent Psychiatry*, 53(5), pp.509-517.

Gibbs, D.A., Martin, S.L., Kupper, L.L. and Johnson, R.E. (2007). Child Maltreatment in Enlisted Soldiers' Families During Combat-Related Deployments. *JAMA*, 298(5), p.528.

Glancy Report (1974). *Working Party Report on security in the NHS*. Psychiatric Hospitals. London: HMSO.

Godier-McBard, L.R., Ibbitson, L., Hooks, C. and Fossey, M. (2019). Military spouses with deployed partners are at greater risk of poor perinatal mental health: a scoping review. *BMJ Military Health*, 165(5), pp.363–370. Available at: [https://militaryhealth.bmj.com/content/jramc/165/5/363.full.pdf?casa\\_token=hRXcZock-JwAAAAA:pVEgzgopaSOBTc\\_Kj8k-\\_8\\_-vbmEvlp-ZfCSdAAfYL8nfgzSraBVYtrB9zZsR8TcFfqJRN-7o2i](https://militaryhealth.bmj.com/content/jramc/165/5/363.full.pdf?casa_token=hRXcZock-JwAAAAA:pVEgzgopaSOBTc_Kj8k-_8_-vbmEvlp-ZfCSdAAfYL8nfgzSraBVYtrB9zZsR8TcFfqJRN-7o2i) (Accessed on: 23 Oct. 2021).

Goffman, E. (1963). *Stigma: Notes on the Management of Spoiled Identity*. London: Penguin Books.

Gorman, G.H., Eide, M. and Hisle-Gorman, E. (2010). Wartime Military Deployment and Increased Pediatric Mental and Behavioral Health Complaints. *Pediatrics*, 126(6), pp.1058–1066.

Glaser, B. (1992). *Emergence v Forcing Basics of Grounded Theory Analysis*. Mill Valley, CA: Sociology Press.

Glaser, B. (1998). *Doing Grounded Theory: Issues and Discussions*. Mill Valley, CA: Sociology Press.

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Mill Valley, CA: Sociology Press.

Goodday, S.M., Shuldiner, J., Bondy, S. and Rhodes, A.E. (2017). Exposure to parental psychopathology and offspring's risk of suicide-related thoughts and behaviours: a systematic review. *Epidemiology and Psychiatric Sciences*, 28(2), pp.179–190.

Goodman, S. H., & Gotlib, I. H. (1999). Risk for psychopathology in the children of depressed mothers: a developmental model for understanding mechanisms of transmission. *Psychological review*, 106(3), pp.458–490. Available at: <https://doi.org/10.1037/0033-295x.106.3.458>

Goodyear, M., Hill, T.-L., Allchin, B., McCormick, F., Hine, R., Cuff, R. and O'Hanlon, B. (2015). Standards of practice for the adult mental health workforce: Meeting the needs of families where a parent has a mental illness. *International Journal of Mental Health Nursing*, 24(2), pp.169–180.

Gould, N. (2006). *Mental Health and Child Poverty*. York: Joseph Rowntree Foundation Available at: <https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/9781859354919.pdf> (Accessed on 08 May 2022).



- Gow, R.L., Choo, M., Darjee, R., Gould, S. and Steele, J. (2010). A demographic study of the Orchard Clinic: Scotland's first medium secure unit. *Journal of Forensic Psychiatry & Psychology*, 21(1), pp.139–155.
- Graham-Bermann, S. A., Gruber, G., Howell, K. H., & Girz, L. (2009). Factors discriminating among profiles of resilience and psychopathology in children exposed to intimate partner violence (IPV). *Child Abuse & Neglect*, 33(9), pp. 648–660.
- Grant, A. and Reupert, A. (2016). The Impact of Organizational Factors and Government Policy on Psychiatric Nurses' Family-Focused Practice With Parents Who Have Mental Illness, Their Dependent Children, and Families in Ireland. *Journal of Family Nursing*, 22(2), pp.199–223.
- Grant, A., Reupert, A., Maybery, D. and Goodyear, M. (2018). Predictors and enablers of mental health nurses' family-focused practice. *International Journal of Mental Health Nursing*, 28(1), pp.140–151.
- Gratz, K., Kiel, E., Latzman, R., Elkin, T., Moore, S. and Tull, M., (2014). Emotion: Empirical Contribution: Maternal Borderline Personality Pathology and Infant Emotion Regulation: Examining the Influence of Maternal Emotion-Related Difficulties and Infant Attachment. *Journal of Personality Disorders*, 28(1), pp.52-69.
- Gregg, L., Adderley, H., Calam, R. and Wittkowski, A. (2021). The implementation of family-focused practice in adult mental health services: A systematic review exploring the influence of practitioner and workplace factors. *International Journal of Mental Health Nursing*, 30(4), pp.885–906.
- Gunlicks, M.L. and Weissman, M.M. (2008). Change in child psychopathology with improvement in parental depression: a systematic review. *J Am Acad Child Adolesc Psychiatry*, 47, pp. 379-89.
- Gunn, J. and Robertson, G. (1976). Drawing a criminal profile. *British Journal of Criminology* 16, pp. 156-60.
- Gunn, J. and Taylor, P. J. (eds.). (2014). *Forensic Psychiatry. Clinical, legal and ethical issues*. Second Edition. Boca Raton, Florida: CRC Press.

## H

- Hameed, M.A. and Lewis, A.J. (2016). Offspring of parents with schizophrenia: a systematic review of developmental features across childhood. *Harv rev Psychiatry*, 24, pp. 104-17.

Hammerton, G., Zammit, S., Mahedy, L., Pearson, R.M., Sellers, R., Thapar, A. and Collishaw, S. (2015). Pathways to Suicide-Related Behavior in Offspring of Mothers With Depression: The Role of Offspring Psychopathology. *Journal of the American Academy of Child & Adolescent Psychiatry*, 54(5), pp.385–393.

Hammerton, G., Zammit, S., Thapar, A. and Collishaw, S. (2016). Explaining risk for suicidal ideation in adolescent offspring of mothers with depression. *Psychological Medicine*, 46(02), pp.265–275.

Hannan, R. (2013). The Triangle of Care: carers included. *Journal of Public Mental Health*, 12(3), pp. 171-172.

Hare Duke, L., Furtado, V., Guo, B. and Völlm, B.A. (2018). Long-stay in forensic-psychiatric care in the UK. *Social Psychiatry and Psychiatric Epidemiology*, 53(3), pp.313–321.

Henrich, J., Heine, S. J., Norenzayan, A. (2010). The weirdest people in the world? *Behavioral & Brain Sciences*, 33, pp. 61–83

Herr, N.R., Hammen, C. and Brennan, P.A. (2008). Maternal Borderline Personality Disorder Symptoms and Adolescent Psychosocial Functioning. *Journal of Personality Disorders*, 22(5), pp.451–465.

Hillenbrand, E.D. (1976). Father Absence in Military Families. *The Family Coordinator*, 25(4), p.451.

Hipwell, A., Keenan, K., Kasza, K., Loeber, R., Stouthamer-Loeber, M. and Bean, T. (2008). Reciprocal Influences Between Girls' Conduct Problems and Depression, and Parental Punishment and Warmth: A Six year Prospective Analysis. *Journal of Abnormal Child Psychology*, 36(5), pp.663–677.

Hobson, R., Patrick, M., Crandell, L., Garcia-perez, R. and Lee, A., (2005). Personal relatedness and attachment in infants of mothers with borderline personality disorder. *Development and Psychopathology*, 17(2), pp. 329-47.

Hopkins, K., Uhrig, N., Colahan, M. (2016). *Association between being male or female and being sentenced to prison in England and Wales in 2015*. London: Ministry of Justice, UK Government. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/571737/associations-between-sex-and-sentencing-to-prison.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/571737/associations-between-sex-and-sentencing-to-prison.pdf) (Accessed on 08 May 2022).

Houtepen, L.C., Heron, J., Suderman, M.J., Fraser, A., Chittleborough, C.R. and Howe, L.D. (2020). Associations of adverse childhood experiences with educational attainment and adolescent health and the role of family and socioeconomic factors: A prospective cohort study in the UK. *PLOS Medicine*, 17(3). e1003031. Available at: <https://doi.org/10.1371/journal.pmed.1003031> (Accessed on: 20 May 2022).

Huebner, A.J., Mancini, J.A., Wilcox, R.M., Grass, S.R. and Grass, G.A. (2007). Parental Deployment and Youth in Military Families: Exploring Uncertainty and Ambiguous Loss. *Family Relations*, 56(2), pp.112–122.

Huntington, C., Newton, J., Donaldson, N., Liossi, C., Reynolds, P., Alharatani, R. and Hosey, M., (2017). Lessons learned on recruitment and retention in hard-to-reach families in a phase III randomised controlled trial of preparatory information for children undergoing general anaesthesia. *BMC Oral Health*, 17(1).

## J

Jaffee, S.R., Moffitt, T.E., Caspi, A. and Taylor, A. (2003). Life With (or Without) Father: The Benefits of Living With Two Biological Parents Depend on the Father's Antisocial Behavior. *Child Development*, 74(1), pp.109–126.

Jellinek, M.S. and Bishop, S.J. (1991). Screening for dysfunction in the children of outpatients at a psychopharmacology clinic. *American Journal of Psychiatry*, 148(8), pp.1031-1036.

Jones, S.H. and Bentall, R.P. (2008). A review of potential cognitive and environmental risk markers in children of bipolar parents. *Clin Psychol Rev*, 28, pp.1083-95.

Joormann, J., Talbot, L. and Gotlib, I., (2007). Biased processing of emotional information in girls at risk for depression. *Journal of Abnormal Psychology*, 116(1), pp.135-143.

## K

Kalebic, N., Adams, A., Bezecsky, Z., Argent, S., Bagshaw, R. and Taylor, P.J. (2020). Social workers' perspectives on people parenting while patients in a secure hospital. *The Journal of Forensic Psychiatry & Psychology*, 31(3), pp.364–384.

Kalebic, N., Thomas, T., Argent, S. and Taylor, P. (2021). To what extent do children of parents/carers who are/have been imprisoned feel stigma? A systematic review. PROSPERO 2021 CRD42021261627 Available at: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42021261627](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021261627) (Accessed on: 30 April 2022).

Kamperman, A.M., Veldman-Hoek, M.J., Wesseloo, R., Robertson Blackmore, E. and Bergink, V. (2017). Phenotypical characteristics of postpartum psychosis: A clinical cohort study. *Bipolar Disorders*, 19(6), pp.450–457.

Kasmi, Y., Duggan, C. and Völlm, B. (2020). A comparison of long-term medium secure patients within NHS and private and charitable sector units in England. *Criminal Behaviour and Mental Health*, 30(1), pp.38–49.

Kent, J., Taylor, P., Argent, S., & Kalebic, N. (2021). Experiences of children who have been separated from a parent due to military deployment: a systematic review of reviews. *BJPsych Open*, 7(S1), pp. S263-S263. Available at: doi:10.1192/bjo.2021.702

Kerr, D.C.R., Owen, L.D. and Capaldi, D.M. (2008). Suicidal ideation and its recurrence in boys and men from early adolescence to early adulthood: An event history analysis. *Journal of Abnormal Psychology*, 117(3), pp.625–636.

Kimball, E. (2015). Edleson Revisited: Reviewing Children’s Witnessing of Domestic Violence 15 Years Later. *Journal of Family Violence*, 31(5), pp.625–637.

King, C.A., Kerr, D.C.R., Passarelli, M.N., Foster, C.E. and Merchant, C.R. (2009). One-Year Follow-Up of Suicidal Adolescents: Parental History of Mental Health Problems and Time to Post-Hospitalization Attempt. *Journal of Youth and Adolescence*, 39(3), pp.219–232.

Kiss, E., Gentzler, A.M., George, C., Kapornai, K., Tamás, Z., Kovacs, M. and Vetró, Á. (2007). Factors influencing mother–child reports of depressive symptoms and agreement among clinically referred depressed youngsters in Hungary. *Journal of Affective Disorders*, 100(1-3), pp.143–151.

Klimes-Dougan, B., Jeong, J., Kennedy, K.P., Allen, T.A. (2017). Intellectual functioning in offspring of parents with bipolar disorder: a review of the literature. *Brain Sci*, 7(11), article number 143 (no page numbers available).

Kumar, R., Marks, M., Platz, C. and Yoshida, K. (1995). Clinical survey of a psychiatric mother and baby unit: characteristics of 100 consecutive admissions. *Journal of Affective Disorders*, 33(1), pp.11–22.

Kuramoto, S.J., Stuart, E.A., Runeson, B., Lichtenstein, P., Langstrom, N. and Wilcox, H.C. (2010). Maternal or Paternal Suicide and Offspring’s Psychiatric and Suicide-Attempt Hospitalization Risk. *Pediatrics*, 126(5), pp.e1026–e1032.

## L

Lacey, R.E., Howe, L.D., Kelly-Irving, M., Bartley, M. and Kelly, Y. (2020). The Clustering of Adverse Childhood Experiences in the Avon Longitudinal Study of Parents and Children: Are Gender and Poverty Important? *Journal of Interpersonal Violence*, 37 (5-6) pp. 2218-2241.

- Lagdon, S., Grant, A., Davidson, G., Devaney, J., Donaghy, M., Duffy, J., Galway, K. and McCartan, C. (2021). Families with Parental Mental Health Problems: A Systematic Narrative Review of Family-Focused Practice. *Child Abuse Review*, 30(5), pp. 400-421.
- Landstedt, E. and Almquist, Y.B. (2019). Intergenerational patterns of mental health problems: the role of childhood peer status position. *BMC Psychiatry*, 19, article number 286. Available at: <https://bmcpsy psychiatry.biomedcentral.com/articles/10.1186/s12888-019-2278-1> (Accessed on: 20 May 2022).
- Lapalme, M., Hodgins, S., LaRoche, C. (1997). Children of parents with bipolar disorder: a metaanalysis of risk for mental disorders. *Can J Psychiatry*, 42, pp. 623-31.
- Lau, P., Hawes, D.J., Hunt, C., Frankland, A., Roberts, G. and Mitchell, P.B. (2017). Prevalence of psychopathology in bipolar high-risk offspring and siblings: a meta-analysis. *European Child & Adolescent Psychiatry*, 27(7), pp.823–837.
- Lauritzen, C., Reedtz, C., Van Doesum, K. and Martinussen, M. (2014). Factors that may Facilitate or Hinder a Family-Focus in the Treatment of Parents with a Mental Illness. *Journal of Child and Family Studies*, 24(4), pp.864–871.
- Leijdesdorff, S., van Doesum, K., Popma, A., Klaassen, R., van Amelsvoort, T. (2017). Prevalence of psychopathology in children of parents with mental illness and/or addiction: an up to date narrative review. *Curr Opin Psychiatry*, 30, pp. 312-7.
- Lelliott, P., Audini, B. and Duffett, R. (2001). Survey of patients from an inner-London health authority in medium secure psychiatric care. *British Journal of Psychiatry*, 178(1), pp.62–66.
- Lester, P., Peterson, K., Reeves, J., Knauss, L., Glover, D., Mogil, C., Duan, N., Saltzman, W., Pynoos, R., Wilt, K. and Beardslee, W. (2010). The Long War and Parental Combat Deployment. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(4), pp.310–320.
- Leve, L.D., Kim, H.K. and Pears, K.C. (2005). Childhood Temperament and Family Environment as Predictors of Internalizing and Externalizing Trajectories From Ages 5 to 17. *Journal of Abnormal Child Psychology*, 33(5), pp.505–520.
- Lewinsohn, P.M., Olino, T.M. and Klein, D.N. (2005). Psychosocial impairment in offspring of depressed parents. *Psychological Medicine*, 35(10), pp.1493–1503.
- Lieb, R., Bronisch, T., Höfler, M., Schreier, A. and Wittchen, H.-U. (2005). Maternal Suicidality and Risk of Suicidality in Offspring: Findings From a Community Study. *American Journal of Psychiatry*, 162(9), pp.1665–1671.
- Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia bulletin*, 30(3), pp. 511-541.

Ljung, T., Lichtenstein, P., Sandin, S., D'Onofrio, B., Runeson, B., Långström, N. and Larsson, H. (2012). Parental schizophrenia and increased offspring suicide risk: exploring the causal hypothesis using cousin comparisons. *Psychological Medicine*, 43(3), pp.581–590.

Lockwood, K. (2018). Disrupted mothering: narratives of mothers in prison. In: Taylor, T., and Bloch, K. (eds.) *Marginalised Mothers, Mothering from the Margins*. London: Emerald Publishing, pp. 157–173.

Lockwood, K., Long, T., Loucks, N., Raikes, B. and Sharratt, K. (2021). A double-edged sword: Children's experiences of visiting a parent in prison in Scotland. *Probation Journal*, 69(2), pp. 159-176.

Loeber, R., Hipwell, A., Battista, D., Sembower, M. and Stouthamer-Loeber, M. (2009). Intergenerational Transmission of Multiple Problem Behaviors: Prospective Relationships between Mothers and Daughters. *Journal of Abnormal Child Psychology*, 37(8), pp.1035–1048.

Low, S.M. and Stocker, C. (2005). Family Functioning and Children's Adjustment: Associations Among Parents' Depressed Mood, Marital Hostility, Parent-Child Hostility, and Children's Adjustment. *Journal of Family Psychology*, 19(3), pp.394–403.

Lyle, D. S. (2006). Using Military Deployments and Job Assignments to Estimate the Effect of Parental Absences and Household Relocations on Children's Academic Achievement. *Journal of Labor Economics*, 24(2), pp.319–350.

## M

Macfie, J., Swan, S., Fitzpatrick, K., Watkins, C. and Rivas, E., (2014). Mothers with borderline personality and their young children: Adult Attachment Interviews, mother–child interactions, and children's narrative representations. *Development and Psychopathology*, 26(2), pp.539-551.

Macfie, J. and Swan, S.A. (2009). Representations of the caregiver–child relationship and of the self, and emotion regulation in the narratives of young children whose mothers have borderline personality disorder. *Development and Psychopathology*, 21(3), pp.993–1011. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2825084/> (Accessed on: 18 December 2019).

Maddocks, S., Johnson, S., Wright, N. and Stickley, T. (2010). A phenomenological exploration of the lived experience of mental health nurses who care for clients with enduring mental health problems who are parents. *Journal of Psychiatric and Mental Health Nursing*, 17(8), pp.674–682.

Maniglio, R. (2009). The impact of child sexual abuse on health: A systematic review of reviews. *Clinical Psychology Review*, 29(7), pp.647–657.

Maoz, H., Goldstein, T., Axelson, D.A., Goldstein, B.I., Fan, J., Hickey, M.B., Monk, K., Sakolsky, D., Diler, R.S., Brent, D., Iyengar, S., Kupfer, D.J. and Birmaher, B. (2013). Dimensional psychopathology in preschool offspring of parents with bipolar disorder. *Journal of Child Psychology and Psychiatry*, 55(2), pp.144–153.

Marantz, S., and Coates, S. (1991). Mothers of Boys with Gender Identity Disorder: A Comparison of Matched Controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 30(2), pp.310-315.

Martin, J., Tilling, K., Hubbard, L., Stergiakouli, E., Thapar, A., Davey Smith, G., O'Donovan, M. and Zammit, S., (2016). Association of Genetic Risk for Schizophrenia With Nonparticipation Over Time in a Population-Based Cohort Study. *American Journal of Epidemiology*, 183(12), pp.1149-1158.

Mason, R., Wolf, M., O'Rinn, S. and Ene, G. (2017). Making connections across silos: intimate partner violence, mental health, and substance use. *BMC Women's Health*, 17(1). Available at: doi: [10.1186/s12905-017-0372-4](https://doi.org/10.1186/s12905-017-0372-4) (Accessed on: 20 May 2022).

Matlin, S.L., Champine, R.B., Strambler, M.J., O'Brien, C., Hoffman, E., Whitson, M., Kolka, L. and Tebes, J.K. (2019). A Community's Response to Adverse Childhood Experiences: Building a Resilient, Trauma-Informed Community. *American Journal of Community Psychology*, 64(3-4), pp. 451-466.

McCarroll, J.E., Fan, Z., Newby, J.H. and Ursano, R.J. (2008). Trends in US Army child maltreatment reports: 1990–2004. *Child Abuse Review*, 17(2), pp.108–118.

McCartan, C., Davidson, G., Donaghy, M., Grant, A., Bunting, L., Devaney, J. and Duffy, J. (2022), 'Are we starting to 'think family'? evidence from a case file audit of parents and children supported by mental health, addictions and children's services'. *Child Abuse Review*. Available at: <https://doi.org/10.1002/car.2738>

McCormick, L., Crawford, M., Anderson, R., Gittelsohn, J., Kingsley, B. and Upson, D., (1999). Recruiting Adolescents into Qualitative Tobacco Research Studies: Experiences and Lessons Learned. *Journal of School Health*, 69(3), pp.95-99.

McKay, M.T., Cannon, M., Healy, C., Syer, S., O'Donnell, L. and Clarke, M.C. (2021). A meta-analysis of the relationship between parental death in childhood and subsequent psychiatric disorder. *Acta Psychiatrica Scandinavica*, 143(6), pp.472–486.

McIntosh, J.E., Tan, E.S., Levendosky, A.A. and Holtzworth-Munroe, A. (2019). Mothers' Experience of Intimate Partner Violence and Subsequent Offspring Attachment Security Ages 1–5 Years: A Meta-Analysis. *Trauma, Violence, & Abuse*, 22(4), pp.885-899. Available at: <https://doi.org/10.1177/1524838019888560> (Accessed on: 29 April 2022).

McNaughton, D.B., Cowell, J.M., Gross, D., Fogg, L. and Ailey, S.H. (2004). The Relationship Between Maternal and Child Mental Health in Mexican Immigrant Families. *Research and Theory for Nursing Practice*, 18(2), pp.229–242.

Mendes, A.V., Loureiro, S.R., Crippa, J.A., de Meneses Gaya, C., García-Esteve, L. and Martín-Santos, R. (2011). Mothers with Depression, School-Age Children with Depression? A Systematic Review. *Perspectives in Psychiatric Care*, 48(3), pp.138–148.

Merrick, M.T., Ford, D.C., Ports, K.A., Guinn, A.S., Chen, J., Klevens, J., Metzler, M., Jones, C.M., Simon, T.R., Daniel, V.M., Ottley, P. and Mercy, J.A. (2019). Vital Signs: Estimated Proportion of Adult Health Problems Attributable to Adverse Childhood Experiences and Implications for Prevention — 25 States, 2015–2017. *MMWR. Morbidity and Mortality Weekly Report*, 68(44), pp.999–1005. Available at: [https://www.cdc.gov/mmwr/volumes/68/wr/mm6844e1.htm?s\\_cid=mm6844e1\\_w#contribAff](https://www.cdc.gov/mmwr/volumes/68/wr/mm6844e1.htm?s_cid=mm6844e1_w#contribAff) (Accessed on 10 Nov. 2019).

Meyer, T.D. and Blechert, J. (2005). Are there attentional deficits in people putatively at risk for affective disorders? *Journal of Affective Disorders*, 84(1), pp.63–72.

Millegan, J., Engel, C., Liu, X., & Dinneen, M. (2013). Parental Iraq/Afghanistan deployment and child psychiatric hospitalization in the US Military. *General Hospital Psychiatry*, 35(5), pp. 556-560. Available at: doi:10.1016/j.genhosppsych.2013.04.015

Ministry of Health (1959). *The Welfare of Children in Hospital, Platt Report*. London: Her Majesty's Stationery Office.

Ministry of Justice (2020). *Statistics on Women and the Criminal Justice System 2019. A Ministry of Justice publication under Section 95 of the Criminal Justice Act 1991*. London: Ministry of Justice.

Mmari, K.N., Bradshaw, C.P., Sudhinaraset, M. and Blum, R. (2010), Exploring the role of social connectedness among military youth: Perceptions from youth, parents, and school personnel. *Child & Youth Care Forum*, 39(5), pp. 351-66.

Moeller, J., Culler, E., Hamilton, M., Aronson, K. and Perkins, D., 2015. The effects of military-connected parental absence on the behavioural and academic functioning of children: a literature review. *Journal of Children's Services*, 10(3), pp.291-306.

Moore, K.E., Stuewig, J.B. and Tangney, J.P. (2016). The Effect of Stigma on Criminal Offenders' Functioning: A Longitudinal Mediation Model. *Deviant Behavior*, 37(2), pp.196–218. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4788463/>. (Accessed on 01 May 2022).



Mulready-Jones A, (2011). Hidden Children, A study into services for Children of Incarcerated Parents in Sweden and the United States. Winston Churchill Memorial Trust, UK: Winston Churchill Memorial Trust. Available at: ([http://www.wcmt.org.uk/sites/default/files/migrated-reports/814\\_1.pdf](http://www.wcmt.org.uk/sites/default/files/migrated-reports/814_1.pdf)) (Accessed on: 17 August 2016).

Murphy, G., Peters, K., Jackson, D. and Wilkes, L. (2011). A qualitative meta-synthesis of adult children of parents with a mental illness. *Journal of Clinical Nursing*, 20(23-24), pp.3430–3442.

Murray, L. (1992). The Impact of Postnatal Depression on Infant Development. *Journal of Child Psychology and Psychiatry*, 33(3), pp.543–561.

Murray, J., Farrington, D.P. and Sekol, I. (2012). Children’s antisocial behavior, mental health, drug use, and educational performance after parental incarceration: A systematic review and meta-analysis. *Psychological Bulletin*, 138(2), pp.175–210. Available at: <https://psycnet.apa.org/fulltext/2012-00399-001.html>.

Murrell, A. R., Christoff, K. A., & Henning, K. R. (2007). Characteristics of domestic violence offenders: associations with childhood exposure to violence. *Journal of Family Violence*, 22(7), pp. 523–532.

Myers, B. J., Mackintosh, V. H., Kumetsova, M. I., Lotze, G. M., Best, A. M., & Ravindran, N. (2013). Teasing, bullying and emotion regulation in children of incarcerated mothers. *Monographs of the Society for Research in Child Development*, 78(3), pp. 26–40. Available at: <http://www.jstor.org/stable/43773253>

## N

Narayan, A.J., Allen, T.A., Cullen, K.R., Klimes-Dougan, B. (2013). Disturbances in reality testing as markers of risk in offspring of parents with bipolar disorder: a systematic review from a developmental psychopathology perspective. *Bipolar disorder*, 15, pp. 723-40.

Nesari, M., Olson, J. K., Vandermeer, B., Slater, L., & Olson, D. M. (2018). Does a maternal history of abuse before pregnancy affect pregnancy outcomes? A systematic review with meta-analysis. *BMC pregnancy and childbirth*, 18(1), p. 404. Available at: <https://doi.org/10.1186/s12884-018-2030-8> (Accessed on: 29 April 2022).

Nesmith, A. and Ruhland, E. (2008). Children of incarcerated parents: Challenges and resiliency, in their own words. *Children and Youth Services Review*, 30(10), pp.1119–1130.

Nevriana, A., Pierce, M., Dalman, C., Wicks, S., Hasselberg, M., Hope, H., Abel, K.M. and Kosidou, K. (2020). Association between maternal and paternal mental illness and risk of injuries in children and adolescents: nationwide register based cohort study in Sweden. *BMJ*, 369, Available at: <https://www.bmj.com/content/369/bmj.m853> (Accessed on: 20 May 2022).

NHS England. (2018). *Service specification: low secure mental health services (Adult)*. London: Department of Health. Accessed at: [Adult-Low-Secure-Service-Specification-SCFT-WSBS-addendum-version.pdf \(england.nhs.uk\)](#) (Accessed on: 02 May 2022).

NHS Health Research Authority (2016). *Defining Research*. London, UK: NHS Health Research Authority. Available at (<http://www.hra.nhs.uk/documents/2016/06/defining-research.pdf>). (Accessed on 17 August 2020).

Niederkrotenthaler, T., Floderus, B., Alexanderson, K., Rasmussen, F. and Mittendorfer-Rutz, E. (2012). Exposure to parental mortality and markers of morbidity, and the risks of attempted and completed suicide in offspring: an analysis of sensitive life periods. *Journal of Epidemiology and Community Health*, 66(3), pp.233–239.

Noble-Carr, D., Moore, T. and McArthur, M. (2019). Children's experiences and needs in relation to domestic and family violence: Findings from a meta-synthesis. *Child & Family Social Work*, 25(1), pp.182–191.

Noonan, C.B. and Pilkington, P.D. (2020). Intimate partner violence and child attachment: A systematic review and meta-analysis. *Child Abuse & Neglect*, 109. Available at: DOI: [10.1016/j.chiabu.2020.104765](https://doi.org/10.1016/j.chiabu.2020.104765) (Accessed on: 20 May 2022).

## O

O'Brien, L., Anand, M., Brady, P. and Gillies, D. (2011a). Children visiting parents in inpatient psychiatric facilities: Perspectives of parents, carers, and children. *International Journal of Mental Health Nursing*, 20(2), pp.137–143.

O'Brien, L., Brady, P., Anand, M. and Gillies, D. (2011b). Children of parents with a mental illness visiting psychiatric facilities: Perceptions of staff. *International Journal of Mental Health Nursing*, 20(5), pp.358–363.

Office for National Statistics. *People in families by family type and presence of children, regions of England and UK constituent countries*. 2015-2021 dataset edition. Richmond, Surrey: Office for National Statistics. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/datasets/peopleinfamiliesbyfamilytypeandpresenceofchildrenregionsofenglandandukconstituentcountries> (Accessed on 08 May 2022).

Ofsted (2013). What about the children? Manchester: Ofsted. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/419128/What about the children.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/419128/What_about_the_children.pdf) (Accessed on: 20 May 2022).

Osborne, L.M. (2018). Recognizing and Managing Postpartum Psychosis: A Clinical Guide for Obstetric Providers. *Obstetrics and gynecology clinics of North America*, 45(3), pp.455–468. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6174883/>.

## P

Parrott, F.R., Macinnes, D. I. and Parrott, J. (2015). Mental illness and parenthood: being a parent in secure psychiatric care. *Criminal Behaviour and Mental Health*, 25(4), pp.258–272.

Parry, B. L. (1995). Postpartum psychiatric syndromes, in Kaplan, H., and Sadock, B (eds.). *Comprehensive Textbook of Psychiatric disorders*, 6th edn. vol 1. Baltimore: Lippincott Williams & Wilkins, pp. 1059–1066.

Pastor-Moreno, G., Ruiz-Pérez, I., Henares-Montiel, J., Escribà-Agüir, V., Higuera-Callejón, C., & Ricci-Cabello, I. (2020). Intimate partner violence and perinatal health: a systematic review. *BJOG : an international journal of obstetrics and gynaecology*, 127(5), pp. 537–547. Available at: <https://doi.org/10.1111/1471-0528.16084>. (Accessed on: 29 April 2022).

Patel, M., Doku, V., and Tennakoon, L. (2003). Challenges in recruitment of research participants. *Advances in Psychiatric Treatment*, 9(3), pp. 229–238. Available at: doi:10.1192/apt.9.3.229

Pesonen, A. K., Räikkönen, K., Heinonen, K., Kajantie, E., Forsén, T., & Eriksson, J. G. (2007). Depressive symptoms in adults separated from their parents as children: a natural experiment during World War II. *American journal of epidemiology*, 166(10), pp. 1126–1133. Available at: <https://doi.org/10.1093/aje/kwm254> (Accessed on: 29 April 2022).

Petfield, L., Startup, H., Droscher, H. and Cartwright-Hatton, S. (2015). Parenting in mothers with borderline personality disorder and impact on child outcomes. *Evidence Based Mental Health*, 18(3), pp.67–75.

Pilowsky, D.J., Wickramaratne, P.J., Rush, A.J., Hughes, C.W., Garber, J., Malloy, E., King, C.A., Cerda, G., Sood, A.B., Alpert, J.E., Wisniewski, S.R., Trivedi, M.H., Talati, A., Carlson, M.M., Liu, H.H., Fava, M. and Weissman, M.M. (2006). Children of Currently Depressed Mothers. *The Journal of Clinical Psychiatry*, 67(01), pp.126–136.

Pilowsky, D.J., Wickramaratne, P., Talati, A., Tang, M., Hughes, C.W., Garber, J., Malloy, E., King, C., Cerda, G., Sood, A.B., Alpert, J.E., Trivedi, M.H., Fava, M., Rush, A.J., Wisniewski, S. and Weissman, M.M. (2008). Children of Depressed Mothers 1 Year After the Initiation of Maternal Treatment: Findings From the STAR\*D-Child Study. *American Journal of Psychiatry*, 165(9), pp.1136–1147.

Plass-Christl, A., Haller, A.-C., Otto, C., Barkmann, C., Wiegand-Grefe, S., Hölling, H., Schulte-Markwort, M., Ravens-Sieberer, U. and Klasen, F. (2017). Parents with mental health problems and their children in a German population based sample: Results of the BELLA study. *PLOS ONE*, 12(7), Available at: <https://pubmed.ncbi.nlm.nih.gov/28671981/> (Accessed on: 20 May 2022).

Poletti, M., Gebhardt, E., Pelizza, L., Preti, A. and Raballo, A. (2020). Looking at Intergenerational Risk Factors in Schizophrenia Spectrum Disorders: New Frontiers for Early Vulnerability Identification? *Frontiers in Psychiatry*, 11:566683. Available at: <https://www.frontiersin.org/articles/10.3389/fpsyt.2020.566683/full> (Accessed on: 20 May 2022).

## R

Radicke, A., Barkmann, C., Adema, B., Daubmann, A., Wegscheider, K. and Wiegand-Grefe, S. (2021). Children of Parents with a Mental Illness: Predictors of Health-Related Quality of Life and Determinants of Child–Parent Agreement. *International Journal of Environmental Research and Public Health*, 18(2), p.379.

Rasic, D., Hajek, T., Alda, M. and Uher, R. (2014). Risk of Mental Illness in Offspring of Parents With Schizophrenia, Bipolar Disorder, and Major Depressive Disorder: A Meta-Analysis of Family High-Risk Studies. *Schizophrenia Bulletin*, 40(1), pp.28–38.

Reinelt, E., Stopsack, M., Aldinger, M., Ulrich, I., Grabe, H.J. and Barnow, S. (2014). Longitudinal Transmission Pathways of Borderline Personality Disorder Symptoms: From Mother to Child? *Psychopathology*, 47(1), pp.10–16.

Rentz, E.D., Marshall, S.W., Loomis, D., Casteel, C., Martin, S.L. and Gibbs, D.A. (2007). Effect of Deployment on the Occurrence of Child Maltreatment in Military and Nonmilitary Families. *American Journal of Epidemiology*, 165(10), pp.1199–1206.

Reupert, A. and Maybery, D. (2007). Families affected by parental mental illness: A multiperspective account of issues and interventions. *American Journal of Orthopsychiatry*, 77(3), pp.362–369.

Reupert, A., Maybery, D. and Morgan, B. (2015). The family-focused practice of primary care clinicians: a case of missed opportunities. *Journal of Mental Health*, 24(6), pp.357–362.

Reupert, A., Gladstone, B., Helena Hine, R., Yates, S., McGaw, V., Charles, G., Drost, L. and Foster, K. (2021). Stigma in relation to families living with parental mental illness: An integrative review. *International Journal of Mental Health Nursing*, 30(1), pp. 6-26.

Riley, A.W., Coiro, M.J., Broitman, M., Colantuoni, E., Hurley, K.M., Bandeen-Roche, K. and Miranda, J. (2009). Mental Health of Children of Low-Income Depressed Mothers: Influences of Parenting, Family Environment, and Raters. *Psychiatric Services*, 60(3), pp.329–336.

Rodriguez, A.J. and Margolin, G. (2014). Parental Incarceration, Transnational Migration, and Military Deployment: Family Process Mechanisms of Youth Adjustment to Temporary Parent Absence. *Clinical Child and Family Psychology Review*, 18(1), pp.24–49.

Rodríguez-Torres, E., González-Pérez, M.M. and Díaz-Pérez, C. (2021). Barriers and facilitators to the participation of subjects in clinical trials: An overview of reviews. *Contemporary Clinical Trials Communications*, 23, p.100829. Available at: <https://doi.org/10.1016/j.conctc.2021.100829>. (Accessed on: 20 May 2022).

Rothman, K.J., (1990). No adjustments are needed for multiple comparisons. *Epidemiology*, 1, pp. 43–46.

Rothman, K.J., (2013). Six persistent research misconceptions. *J. Gen. Intern. Med.* 29, pp. 1060–1064.

Rüsch, N., Angermeyer, M.C. and Corrigan, P.W. (2005). Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry*, 20(8), pp.529–539.

Rutherford, M. and Duggan, S. (2008). Forensic mental health services: facts and figures on current provision. *The British Journal of Forensic Practice*, 10(4), pp.4–10.

Rutter, M. (1972) *Maternal Deprivation Reassessed*. Harmondsworth: Penguin Education.

Rutter, M. (1979). 'Protective factors in children's responses to stress and disadvantage', in Kent, M.W. and Rolf, J.E. (eds.) *Social competence in children*. Hanover, N.H.: Published For The University Of Vermont By The University Press Of New England, pp. 49-74.

Rutter, M. (1978) 'Family, area and school influences in the genesis of conduct disorders', in Hersov, L.A., Berger, M. and Shaffer, D. (eds.) *Aggression and anti-social behaviour in childhood and adolescence*. Oxford ; Elmsford, N.Y.: Pergamon Press, pp.95-113.

Rutter, M., & Quinton, D. (1984). Parental psychiatric disorder: Effects on children. *Psychological Medicine*, 14, pp. 853–880.

Rutter, M. (2007). Proceeding From Observed Correlation to Causal Inference: The Use of Natural Experiments. *Perspectives on Psychological Science*, 2(4), pp.377–395.

Rutter, M. (2012) "Resilience as a dynamic concept," *Development and Psychopathology*. Cambridge University Press, 24(2), pp. 335–344.

Rutter, M. and Quinton, D. (1984). Parental psychiatric disorder: effects on children'. *Psychological Medicine*, 14(4), pp.853-880.

Rutter, M. and Sroufe, L.A. (2000). Developmental psychopathology: Concepts and challenges. *Development and Psychopathology*, 12(3), pp.265–296.

## S

Salloum, I.M. and Thase, M.E. (2000). Impact of substance abuse on the course and treatment of bipolar disorder. *Bipolar Disorders*, 2(3.2), pp.269–280.

Santavirta, T., Santavirta, N., Betancourt, T.S. and Gilman, S.E. (2015). Long term mental health outcomes of Finnish children evacuated to Swedish families during the second world war and their non-evacuated siblings: cohort study. *BMJ*, 350(1), pp. 7753.

Saunders, V. (2018). What does your dad do for a living? Children of prisoners and their experiences of stigma. *Children and Youth Services Review*, 90, pp.21–27.

Schacht, R., Hammond, L., Marks, M., Wood, B. and Conroy, S. (2013). The Relation between Mind-mindedness in Mothers with Borderline Personality Disorder and Mental State Understanding in their Children. *Infant and Child Development*, 22(1), pp.68–84.

Scott, S. and Gardner, F. (2015). Parenting programs, in Rutter M, Bishop D, Pine D, et al., (eds.). *Rutter's child and adolescent psychiatry*. Oxford: Wiley, pp. 483–95.

Selous, C., Kelly-Irving, M., Maughan, B., Eyre, O., Rice, F. and Collishaw, S. (2019). Adverse childhood experiences and adult mood problems: evidence from a five-decade prospective birth cohort. *Psychological Medicine*, pp.1–8.

Serafini, G., Muzio, C., Piccinini, G., Flouri, E., Ferrigno, G., Pompili, M., Girardi, P. and Amore, M. (2015). Life adversities and suicidal behavior in young individuals: a systematic review. *European Child & Adolescent Psychiatry*, 24(12), pp.1423–1446. Available at: <https://link.springer.com/article/10.1007%2Fs00787-015-0760-y>.

Shahani, L. (2012). A father with postpartum psychosis. *BMJ case reports*, 2012, bcr1120115176. Available at: <https://doi.org/10.1136/bcr.11.2011.5176>

Shah-Anwar, S., Gumley, A. and Hunter, S. (2019). Mental Health Professionals' Perspectives of Family-focused Practice across Child and Adult Mental Health Settings: A Qualitative Synthesis. *Child & Youth Services*, 40(4), pp.383-404.

Shelton, K.H. and Harold, G.T. (2008). Interparental conflict, negative parenting, and children's adjustment: Bridging links between parents' depression and children's psychological distress. *Journal of Family Psychology*, 22(5), pp.712–724.

Siegenthaler, E., Munder, T. and Egger, M. (2012). Effect of preventive interventions in mentally ill parents on the mental health of the offspring: systematic review and meta-analysis. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(1), pp.8-17.e8. Available at: <https://www.ncbi.nlm.nih.gov/pubmed/22176935> (Accessed on: 4 Oct. 2021).

Silk, J., Shaw, D., Forbes, E., Lane, T. and Kovacs, M., (2006). Maternal Depression and Child Internalizing: The Moderating Role of Child Emotion Regulation. *Journal of Clinical Child & Adolescent Psychology*, 35(1), pp.116-126.

Silk, J.S., Ziegler, M.L., Whalen, D.J., Dahl, R.E., Ryan, N.D., Dietz, L.J., Birmaher, B., Axelson, D.A. and Williamson, D.E. (2009). Expressed Emotion in Mothers of Currently Depressed, Remitted, High-Risk, and Low-Risk Youth: Links to Child Depression Status and Longitudinal Course. *Journal of Clinical Child & Adolescent Psychology*, 38(1), pp.36–47.

Silva, E.P., Lemos, A., Andrade, C.H.S. and Ludermir, A.B. (2018). Intimate partner violence during pregnancy and behavioral problems in children and adolescents: a meta-analysis. *Jornal de Pediatria*, 94(5), pp.471–482.

Silverman, A. and Gelles, R.J. (2001). The Double Whammy Revisited: The Impact of Exposure to Domestic Violence and Being a Victim of Parent to Child Violence. *The Indian Journal of Social Work*, 62(3), pp. 305-27.

Sit, D., Rothschild, A. J., & Wisner, K. L. (2006). A review of postpartum psychosis. *Journal of women's health* (2002), 15(4), pp. 352–368. Available at: <https://doi.org/10.1089/jwh.2006.15.352>

Sjöblom, L.-M., Pejler, A. and Asplund, K. (2005). Nurses' view of the family in psychiatric care. *Journal of Clinical Nursing*, 14(5), pp.562–569.

Skinner-Osei, P. and Levenson, J.S. (2018). Trauma-informed services for children with incarcerated parents. *Journal of Family Social Work*, 21(4-5), pp.421–437.

Slack, K. and Webber, M. (2008). Do we care? Adult mental health professionals' attitudes towards supporting service users' children. *Child & Family Social Work*, 13(1), pp.72–79.

Smith, C.J. and Young, D.S. (2017). A Retrospective Look at the Experience of Parental Incarceration and Family Reentry During Adolescence. *Social work in public health*, 32(8), pp.475–488.

Smoller, J.W., Andreassen, O.A., Edenberg, H.J., Faraone, S.V., Glatt, S.J. and Kendler, K.S. (2019). Psychiatric genetics and the structure of psychopathology. *Molecular Psychiatry*, 24(3), pp.409–420.

Somers, N., Bartlett, A. (2014). Women's secure hospital care pathways in practice: a qualitative analysis of clinicians views in England and Wales. *BMC Health Serv Res*, 14, 450. <https://doi.org/10.1186/1472-6963-14-450>

Spilsbury, J. C., Bellistron, L., Drotar, D., Drinkard, A., Kretschmar, J., Creeden, R., & Friedman, S. (2007). Clinically significant trauma symptoms and behavioral problems in a community-based sample of children exposed to domestic violence. *Journal of Family Violence*, 22, pp. 487–499.

Sroufe, L.A. (1997). Psychopathology as an outcome of development. *Development and Psychopathology*, 9(2), pp.251–268.

Sroufe, L.A., Egeland, B. and Kreutzer, T. (1990). The Fate of Early Experience Following Developmental Change: Longitudinal Approaches to Individual Adaptation in Childhood. *Child Development*, 61(5), p.1363.

Stallard, P., Norman, P., Huline-Dickens, S., Salter, E. and Cribb, J. (2004). The Effects of Parental Mental Illness upon Children: A Descriptive Study of the Views of Parents and Children. *Clinical Child Psychology and Psychiatry*, 9(1), pp.39–52.

Stanley, N., (2003). Working on the interface: identifying professional responses to families with mental health and child-care needs. *Health & Social Care in the Community*, 11(3), pp.208-218.

Stepp, S., Whalen, D., Pilkonis, P., Hipwell, A. and Levine, M., (2012). Children of mothers with borderline personality disorder: Identifying parenting behaviors as potential targets for intervention. *Personality Disorders: Theory, Research, and Treatment*, 3(1), pp.76-91.

Strauss, A. and Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedure and Techniques*. Newbury Park, London: Sage.

## T

Talati, A., Wickramaratne, P.J., Pilowsky, D.J., Alpert, J.E., Cerda, G., Garber, J., Hughes, C.W., King, C.A., Malloy, E., Sood, A.B., Verdeli, H., Trivedi, M.H., Rush, A.J. and Weissman, M.M. (2007). Remission of maternal depression and child symptoms among single mothers. *Social Psychiatry and Psychiatric Epidemiology*, 42(12), pp.962–971.



Tchernegovski, P., Hine, R., Reupert, A.E. and Maybery, D.J. (2018a). Adult mental health clinicians' perspectives of parents with a mental illness and their children: single and dual focus approaches. *BMC Health Services Research*, 18(1), Available at: <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-3428-8> (Accessed on: 20 May 2022).

Tchernegovski, P., Reupert, A.E. and Maybery, D.J. (2018b). How do Australian adult mental health clinicians manage the challenges of working with parental mental illness? A phenomenological study. *Child & Family Social Work*, 23, pp. 381-9.

Thomas, L. and Kalucy, R. (2003). Parents with mental illness: Lacking motivation to parent. *International Journal of Mental Health Nursing*, 12(2), pp.153–157.

Thomas, T. Kalebic, N., Argent, S. and Taylor P, J. (2022) 'To what extent do children of parents who have been in prison feel stigma? A systematic review'. Presented at the Royal College of Psychiatrists, Faculty of Forensic Psychiatry Annual Conference 2022

Thulstrup, H.S. and Karlsson, E.L. (2017) Children of Imprisoned Parents and Their Coping Strategies: A Systematic Review. *Societies*, 7(2) p 15. Available at: <https://doi.org/10.3390/soc7020015> (Accessed on: 29 April 2022).

Tompson, M.C., Pierre, C.B., Haber, F.M., Fogler, J.M., Groff, A.R. and Asarnow, J.R. (2007). Family-focused Treatment for Childhood-onset Depressive Disorders: Results of an Open Trial. *Clinical Child Psychology and Psychiatry*, 12(3), pp.403–420.

Toso, K., de Cock, P., & Leavey, G. (2020). Maternal exposure to violence and offspring neurodevelopment: A systematic review. *Paediatric and perinatal epidemiology*, 34(2), pp. 190–203. Available at: <https://doi.org/10.1111/ppe.12651> (Accessed on: 29 April 2022)

Trautmann, J., Alhusen, J. and Gross, D., 2015. Impact of deployment on military families with young children: A systematic review. *Nursing Outlook*, 63(6), pp.656-679.

Tsypes, A. and Gibb, B.E. (2015). Peer Victimization Mediates the Impact of Maternal Depression on Risk for Suicidal Ideation in Girls but not Boys: A Prospective Study. *Journal of Abnormal Child Psychology*, 43(8), pp.1439–1445.

Tully, J., Cappai, A., Lally, J. and Fotiadou, M. (2018). Follow-up study of 6.5 years of admissions to a UK female medium secure forensic psychiatry unit. *BJPsych Bulletin*, 43(2), pp.54–57.

Tully, L., Spyreli, E., Allen-Walker, V., Matvienko-Sikar, K., McHugh, S., Woodside, J., McKinley, M., Kearney, P., Dean, M., Hayes, C., Heary, C. and Kelly, C., (2021). Recruiting 'hard to reach' parents for health promotion research: experiences from a qualitative study. *BMC Research Notes*, 14(1).

## U

UyBico, S.J., Pavel, S. and Gross, C.P., 2007. Recruiting vulnerable populations into research: a systematic review of recruitment interventions. *Journal of general internal medicine*, 22(6), pp.852-863.

UK Government. (2007). *Mental Health Act 2007*. [online] Legislation.gov.uk. Available at: <https://www.legislation.gov.uk/ukpga/2007/12/contents>. (Accessed on: 29 April 2022).

## V

VanderKruik, R., Barreix, M., Chou, D., Allen, T., Say, L. and Cohen, L.S. (2017). The global prevalence of postpartum psychosis: a systematic review. *BMC Psychiatry*, 17(1). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5534064/> (Accessed on: 20 May 2022).

Van Loon, L.M.A., Van de Ven, M.O.M., Van Doesum, K.T.M., Witteman, C.L.M. and Hosman, C.M.H. (2014). The Relation Between Parental Mental Illness and Adolescent Mental Health: The Role of Family Factors. *Journal of Child and Family Studies*, 23(7), pp.1201–1214.

van Santvoort, F., Hosman, C.M., Janssens, J.M., van Doesum, K.T., Reupert, A., van Loon, L.M. (2015). The impact of various parental mental disorders on children's diagnoses: a systematic review. *Clin child fam Psychol Rev*, 18, pp. 281-99.

Vercruyssen, A., Roose, H., Carton, A. and Putte, B.V.D. (2013). The effect of busyness on survey participation: being too busy or feeling too busy to cooperate? *International Journal of Social Research Methodology*, 17(4), pp.357–371.

Veri, S., Muthoni, C., Boyd, A.S. and Wilmoth, M. (2021). A Scoping Review of the Effects of Military Deployment on Reserve Component Children. *Child & Youth Care Forum*, 50(4), pp. 743-777.

Völlm, B.A., Edworthy, R., Huband, N., Talbot, E., Majid, S., Holley, J., Furtado, V., Weaver, T., McDonald, R. and Duggan, C. (2018). Characteristics and Pathways of Long-Stay Patients in High and Medium Secure Settings in England; A Secondary Publication From a Large Mixed-Methods Study. *Frontiers in Psychiatry*, 9, Available at: <https://www.frontiersin.org/articles/10.3389/fpsyt.2018.00140/full> (Accessed 02 May 2022).

## W

Ward, B., Reupert, A., McCormick, F., Waller, S. and Kidd, S. (2017). Family-focused practice within a recovery framework: practitioners' qualitative perspectives. *BMC Health Services Research*, 17(1). Available at: <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2146-y> (Accessed on: 20 May 2022).

Waddington, C.H. (1957). *The strategy of the genes : a discussion of some aspects of theoretical biology*. London: George Allen & Unwin.

Webb, R., Abel, K., Pickles, A., Appleby, L. (2005). Mortality in offspring of parents with psychotic disorders: a critical review and meta-analysis. *Am J Psychiatry*, 162, pp.1045-56.

Weissman, M.M., Pilowsky, D.J., Wickramaratne, P.J., Talati, A., Wisniewski, S.R., Fava, M., Hughes, C.W., Garber, J., Malloy, E., King, C.A., Cerda, G., Sood, A.B., Alpert, J.E., Trivedi, M.H., Rush, A.J. and STAR\*D-Child Team (2006). Remissions in Maternal Depression and Child Psychopathology. *JAMA*, 295(12), p.1389.

Wells, M., Hartwright, C., Morgan, S. and Gale, L., 2021. "My Kids Will Always Be around Me, if Not Physically, Spiritually They Will Always Be around Me": Fathers in Forensic Inpatient Care. *Journal of Forensic Psychology Research and Practice*, 22(2), pp.142-185.

Welsh Government. (2015). *Child Poverty Strategy for Wales*. Available at: <https://gov.wales/sites/default/files/publications/2019-06/child-poverty-strategy-for-wales-report.pdf> (Accessed on: 07 May 2022).

Welsh Government. (2017). *Transforming Children and Young People's Mental Health Provision: a Green Paper*. Available at: [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/664855/Transforming children and young people s mental health provision.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/664855/Transforming_children_and_young_people_s_mental_health_provision.pdf) (Accessed on: 07 May 2022).

Welsh Government. (2020). *Curriculum for Wales. The journey to 2022*. Cardiff: Welsh Government. Available at: <https://hwb.gov.wales/api/storage/cbe5e2c9-16cf-4eb7-87a1-c1a64fc598d8/the-journey-to-2022.pdf> (Accessed on: 08 May 2022).

Welsh Government. (2021). *Framework on embedding a whole-school approach to emotional and mental well-being*. Cardiff: Welsh Government. Available at: <https://gov.wales/sites/default/files/publications/2021-03/framework-on-embedding-a-whole-school-approach-to-emotional-and-mental-well-being.pdf> (Accessed on: 08 May 2022).

Welsh Government. (2022). *Persistent poverty: 2020*. Based on statistics from the Understanding Society Survey (not referenced). Available at: <https://gov.wales/persistent-poverty-2020> (Accessed on: 07 May 2022).

West-Smith Mary F (2007). Dad's in prison: Life histories of the children of incarcerated fathers. Ph.D. dissertation, Denver, Colorado: School of Public Affairs, University of Colorado.

White, H., Flanagan, T., Martin, A. and Silvermann, D., (2011a). Mother–infant interactions in women with borderline personality disorder, major depressive disorder, their co-occurrence, and healthy controls. *Journal of Reproductive and Infant Psychology*, 29(3), pp.223-235.

White, C., de Burgh, H., Fear, N. and Iversen, A., (2011b). The impact of deployment to Iraq or Afghanistan on military children: A review of the literature. *International Review of Psychiatry*, 23(2), pp.210-217.

Wiegand-Grefe, S., Sell, M., Filter, B. and Plass-Christl, A. (2019). Family Functioning and Psychological Health of Children with Mentally Ill Parents. *International Journal of Environmental Research and Public Health*, 16(7), p.1278.

Wilde, A., Chan, H.-N. ., Rahman, B., Meiser, B., Mitchell, P.B., Schofield, P.R. and Green, M.J. (2014). A meta-analysis of the risk of major affective disorder in relatives of individuals affected by major depressive disorder or bipolar disorder. *Journal of Affective Disorders*, 158, pp.37–47.

Weiss, M. Zelkowitz, P. Feldman R.B., et al. (1996). Psychopathology in offspring of mothers with borderline personality disorder: A pilot study. *Can J Psychiatry*, 41, pp.285-90.

Weissman, M.M., Berry, O.O., Warner, V., Gameroff, M.J., Skipper, J., Talati, A., Pilowsky, D.J. and Wickramaratne, P. (2016). A 30-Year Study of 3 Generations at High Risk and Low Risk for Depression. *JAMA Psychiatry*, 73(9), p.970.

Williams, H.K., Senanayke, M., Ross, C.C., Bates, R. and Davoren, M. (2020). Security needs among patients referred for high secure care in Broadmoor Hospital England. *BJPsych Open*, 6(4).

Williamson, V., Stevelink, S.A.M., Da Silva, E. and Fear, N.T. (2018). A systematic review of wellbeing in children: a comparison of military and civilian families. *Child and Adolescent Psychiatry and Mental Health*, 12(46). Available at: <https://capmh.biomedcentral.com/articles/10.1186/s13034-018-0252-1#citeas> (Accessed on: 20 May 2022).

World Health Organisation. (2013). Mental health action plan 2013-2020. Available at: <https://www.who.int/publications/i/item/9789241506021> (Accessed on: 20 May 2022).

## Y

Yamamoto, R. and Keogh, B. (2018). Children's experiences of living with a parent with mental illness: A systematic review of qualitative studies using thematic analysis. *Journal of Psychiatric and Mental Health Nursing*, 25(2), pp.131–141.

## Z

Zalewski, M., Stepp, S., Scott, L., Whalen, D., Beeney, J. and Hipwell, A., (2014). Maternal Borderline Personality Disorder Symptoms and Parenting of Adolescent Daughters. *Journal of Personality Disorders*, 28(4), pp.541-554.

Zhang, J. and Flynn, C. (2020). 'University students/graduates who have experienced parental incarceration: A qualitative exploratory study of protective processes', *Qualitative Social Work*, 19(5–6), pp. 882–900.

## APPENDICES

**Appendix A. Inclusion and exclusion criteria for the review of systematic reviews on parental psychiatric disorder.**

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Study design</b>	Systematic reviews <sup>1</sup> of quantitative data, which used meta-analysis or narrative synthesis	Qualitative reviews Reviews which were not systematic in methods <sup>1</sup> Original research papers/conference papers/grey literature/books/book chapters/dissertations/editorials
<b>Study style</b>	Full text available in English Published in a peer reviewed journal	Full text not available in English Not apparently peer reviewed
<b>Parent definition</b>	Biological father or mother, adoptive parent, stepparent or other adult in an enduring/legal parenting role Any parent age or gender	No enduring parental role with the child/offspring
<b>Parental mental illness/disorder</b>	The parent had, or had had, a major mental disorder defined by either ICD <sup>2</sup> /DSM <sup>3</sup> categorical approaches or a recognised assessment/screening tool with a threshold indicative of mental disorder <sup>4</sup> . Reviews in which at least 50% of papers followed this pattern were included <sup>5</sup>	Reviews in which over 50% of papers examined parental symptoms, or traits of mental disorder, not reaching diagnostic threshold  Reviews in which over 50% of papers <i>only</i> included parents whose <i>only</i> disorder was: <ul style="list-style-type: none"> <li>- Substance misuse related</li> <li>- Intellectual disability</li> <li>- Post-traumatic stress disorder as the primary diagnosis</li> <li>- Mild depression and/or anxiety</li> </ul>
<b>Timing of the parental mental illness/disorder</b>	The parental mental illness/disorder occurred when the child was aged 1 year or older (no maximum offspring age) <ul style="list-style-type: none"> <li>- reviews which included some papers which studied the perinatal period, but in which at least 50% of included papers examined children older than one year</li> </ul>	Reviews including over 50% of papers which <i>only</i> consider parental mental illness/disorder confined to perinatal period (children up to one year of age)
<b>Offspring demographics</b>	Any (but see age exclusion)	Reviews including over 50% of papers which <i>only</i> consider the perinatal period (children up to one year of age)
<b>Offspring outcomes</b>	At least one of the outcome measures sought in the selected review must have been of child experience(s), or child problem(s), or need(s) or strength(s)	Reviews which <i>only</i> reported the effects of parental mental disorder on parenting behaviours, and reported no child measures/outcomes Reviews focussing <i>only</i> on interventions





**Appendix B: Offspring findings of emotional (including suicide and suicide-related behaviours), behavioural, cognitive and social outcomes when a parent has major mental disorder, with detail as to the number of studies which were cited as supporting a finding, or being used in a calculation which supports a finding, within the reviews. This includes review findings with only one supporting study**

Offspring outcome	Parental mental disorder	Parental gender	Offspring finding	Comparison group(s) in the study	Number of studies within the reviews, or (indicated by '2'), the number within a calculation (e.g. meta-analyses), which individually or overall, show evidence for/ against/ or are inconclusive, re the offspring finding			Rv Auth-ors
					For	Against	Inconclusive	
Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)	Schizophrenia	Mother	Significant association between maternal schizophrenia and offspring SRB (OR 1.98) <sup>1</sup>	Offspring of well mothers	N=1 Mittendorf er-Rutz	N=0	N=0	G
		Father	Significant association between paternal schizophrenia and offspring SRB (OR 1.44) <sup>1</sup>	Offspring of well fathers	N=1 Mittendorf er-Rutz	N=0	N=0	G
	Bipolar/ Depression	Mother	Significantly higher rate of SRT and SA in adolescent offspring of mothers with depression or bipolar	Offspring of well mothers	N=2 Klimes- Duggan Weissman	N=0	N=0	G
			Significant association between maternal mood disorder and offspring SRB (NOS) OR 1.43 <sup>1</sup>	Offspring of well mothers (n=1)	N=1 Mittendorf er-Rutz	N=0	N=0	G
			Significant association between maternal mood disorder and offspring:  SRT (persistent) OR 1.9 <sup>1</sup>	Offspring of mothers without mood, alcohol or substance use disorders	N=1  Glowinski	N=0	N=1	G

Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)			SRT (with plan) OR 1.8 <sup>1</sup> SRT (without plan)	As above	Glowinski			
			Association between maternal mood disorder and offspring SA	Offspring of well mothers (n=1)/ mothers without mood, alcohol or substance use disorders (n=2)	N=0	N=0	N=3 Lewinsohn	G
							Glowinski Reyes	
		Father	Significant association between paternal mood disorder and offspring SRB OR 2.2 <sup>1</sup> (offspring suicide attempt)  OR 2.65 <sup>1</sup> (offspring suicide attempt) OR 1.4 <sup>1</sup>	Offspring of fathers without mood or alcohol use disorders (n=1)/ Offspring of well fathers (n=2)	N=3  Glowinski Lewinsohn Mittendorf er-Rutz	N=0	N=0	N=0
			Association between paternal mood disorder and offspring SRT	Offspring of fathers without a mood or alcohol use disorder	N=0	N=0	N=1 Glowinski	G
		Parent NOS	Significant association between parental mood disorder and offspring SA OR 3.2 <sup>1</sup>	Offspring of well parents	N=1 Santana	N=0	N=0	G
			Significant association between parental mood disorder and SA, and offspring SA OR 6.0 <sup>1</sup> OR 4.8 <sup>1</sup> OR 4.1 <sup>1</sup>	Offspring of parents with mood disorder but no SA (n=3)	N=3  Brent 2002 Brent 2015 Burke	N=0	N=0	G
			Significant association between parental mood disorder and offspring SRT OR 5.1 <sup>1,5</sup>	Offspring of well parents	N=1 Sanatana	N=0	N=0	G

Offspring outcome:	Parental mental disorder	Parental gender	Offspring finding	Comparison group(s) in the study	Number of studies within the reviews, or (indicated by '2'), the number within a calculation (e.g. meta-analyses), which individually or overall, show evidence for/against/or are inconclusive, re the offspring finding			Rv authors
					For	Against	Inconclusive	
Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)	Personality disorder	Mother	Offspring of mothers with EUPD had a significantly higher rate of SRT	Offspring of well mothers	N=1 Barnow 2006	N=0	N=0	E, P
			Significant association between maternal PD NOS and offspring SRB (OR 2.14) <sup>1</sup>	Offspring of well mothers	N=1 Mittendorf er-Rutz	N=0	N=0	G
		Father	Significant association between paternal PD NOS and offspring SRB (OR 2.94) <sup>1</sup>	Offspring of well fathers	N=1 Mittendorf er-Rutz	N=0	N=0	G
		Parent	Significant association between parental personality disorder and offspring SRT OR 3.2 <sup>1,5</sup>	Offspring of well parents	N=1 Santana	N=0	N=0	G
			Association between parental PD and offspring SA	Offspring of well parents	N=0	N=0	N=1 Santana	G
	Psychopathology other/ NOS/ combined	Mother	Significant association between maternal SRT and offspring SRT: OR 1.95 <sup>1</sup> OR 1.6 <sup>1</sup>  Association between maternal SRT and offspring SRT	Offspring of mothers without SRT (n=1)/ SRT or SA (n=1)/  SRT or depression (n=1)	N=2  An Lieb	N=0	N=1  Min	G

Offspring outcome:  Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)	Parental mental disorder:  Psychopathology other/ NOS/ combined		Significant association between maternal SA and offspring SRT: OR 4.4 <sup>1</sup> without plan OR 2.17 <sup>1</sup> without plan OR 5.04 <sup>1</sup> with plan	Offspring of mothers without SRT or SA (n=1)/ without SA (n=1)	N=2  Lieb Geulayov Geulayov	N=0	N=0	G
			Significant association between maternal suicide and offspring SRB (NOS): OR 1.79 <sup>1</sup>  OR 1.80 <sup>1</sup>  OR 3.51 <sup>1</sup>	Offspring of well mothers (n=1)/ offspring of mothers who died accidentally(n=1)/ offspring of alive mothers (n=1)	N=3  Mittendorf er-Rutz  Kuramoto  Jakobsen	N=0	N=0	G
			Significant association between maternal SRB and offspring SRB: OR 2.75 <sup>1</sup> (maternal SRB and offspring SRB)  OR 2.94 <sup>1</sup> (maternal SA and offspring SA) OR 5.4 <sup>1</sup> (maternal SA and offspring SA)	Offspring of well mothers (n=1)/ offspring of mothers who have no SA (n=1)/ no SA or SRT (n=1)	N=3 Mittendorf er-Rutz  Geulayov Lieb	N=0	N=0	G
			Significant association between any maternal psychopathology and offspring suicide attempt OR 2.4 <sup>1</sup>	Offspring of mentally well parents	N=1 King	N=0	N=0	G
			Association between maternal SRT and offspring SA	Offspring of mothers who have no SA or SRT	N=0	N=1 Lieb	N=0	G

Offspring outcome:	Parental mental disorder:	Parental gender	Offspring finding	Comparison group(s) in the study	Number of studies within the reviews, or (indicated by '2'), the number within a calculation (e.g. meta-analyses), which individually or overall, show evidence for/against/or are inconclusive, re the offspring finding			Rv authors
					For	Against	Inconclusive	
Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)	Psychopathology other/ NOS/ combined	Father	Significant association between paternal suicide and offspring SRB OR 1.91 <sup>1</sup> OR 2.42 <sup>1</sup>	Offspring of well fathers (n=1)/ alive fathers (n=1)	N=2 Mittendorfer-Rutz Jakobsen	N=0	N=0	G
			Significant association between paternal SRB and offspring SRB OR 1.88 <sup>1</sup>	Offspring of well fathers (n=1)	N=1 Mittendorfer-Rutz	N=0	N=0	G
			Association between paternal SA and offspring SRB	Offspring of fathers who have no SA (n=1)/	N=0	N=0	N=1 Geulayov	G
			Association between paternal psychopathology and offspring SA	Offspring of well parents (n=2)	N=0	N=0	N=1 King	G
			Association between paternal SRT and offspring SRT	Offspring of fathers without SRT (n=1)	N=0	N=0	N=1 An	G
			Association between paternal suicide attempt and offspring SRT (with or without a plan)	Offspring of fathers without SA (n=1)	N=0	N=0	N=1 Geulayov	G
			Association between paternal suicide and offspring SRB	Offspring of fathers who died accidentally (n=1)	N=0	N=0	N=1 Kuramoto	G

Suicide related behaviours (SRB) including suicide related thoughts (SRT) and suicide attempts (SA)	Psychopathology other/ NOS/ combined	'parent'	Significant association between parental psychopathology and offspring SA OR 2.63 <sup>1</sup>	Offspring of well parents	N=1 King	N=0	N=0	G
			Significant association between parental SRB and offspring SRB OR 1.5 <sup>1</sup>	Offspring of fathers who have not had a hospital admission for mental disorder or SRB (n=1)/ not had SRB or completed suicide (n=1)	N=2 Christianse n Niederkrotenthaler	N=0	N=0	G
			OR 2.56 <sup>1</sup>					
			Significant association between parental suicide and offspring SRB OR 1.75 <sup>1</sup>	Offspring of parents with no SRB or suicide	N=1 Niederkrotenthaler	N=0	N=0	G
			Association between parental psychopathology and offspring SRT	Offspring of mentally well parents	N=0	N=0	N=1 Mortier	G
			Association between parental psychopathology and offspring SRB (offspring SRB not otherwise detailed)	Offspring of parents who have not had inpatient treatment for SRB or psychopathology	N=0	N=1	N=2 Christianse n	G
			(offspring SA)	Offspring of mentally well parents			Mortier	
			(offspring SA)	Offspring of mentally well parents with no substance use problems		Isohookana		
				Offspring of parents with no SA/SRT				
			No significant association between parental SA/SRT and offspring SA		N=0	N=0	N=1 Mercy	G

Offspring outcome	Parental mental disorder	Parental gender	Offspring finding	Comparison group(s) in the study	Number of studies within the reviews, or (indicated by '2'), the number within a calculation (e.g. meta-analyses), which individually or overall, show evidence for/against/or are inconclusive, re the offspring finding			Rv authors
					For	Against	Inconclusive	
Completed suicide	Schizophrenia	Mother	Significant association between maternal schizophrenia and offspring suicide (OR 2.1)	Offspring of mothers without schizophrenia	N=1 Ljung	N=0	N=0	G
		Father	Significant association between paternal schizophrenia and offspring suicide (OR 1.92)	Offspring of fathers without schizophrenia	N=1 Ljung	N=0	N=0	G
	Bipolar/Depression	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Personality disorder	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Psychopathology other/ NOS/ combined	Mother	Significant association between any maternal SMI/MD and offspring suicide (OR 1.73) <sup>1</sup>	Offspring of mothers who are alive and have not had a psychiatric admission	N=1 Agerbo	N=0	N=0	G
			Significant association between maternal suicide and offspring suicide OR 6.59 <sup>1</sup> OR 4.75 <sup>1</sup>	Offspring of mothers who are alive (n=1)/ who are alive and have not had a psychiatric admission (n=1)	N=2 Cheng Agerbo	N=0	N=0	G
		Father	Significant association between any paternal SMI/MD and offspring suicide: OR 1.56 <sup>1</sup>	Offspring of fathers who are alive and have not had a psychiatric admission	N=1 Agerbo	N=0	N=0	G

			Significant association between paternal suicide and offspring suicide:  OR 2.3 <sup>1</sup>  OR 5.38 <sup>1</sup>	Offspring of fathers who are alive and have not had a psychiatric admission (n=1) /who are alive (n=1)	N=2  Agerbo  Cheng	N=0	N=0	G
		Parent	Significant association between parental suicide and offspring suicide OR 2.5 <sup>1</sup>	Offspring of parents without SRB/suicide	N=1 Niederkote nthalder	N=0	N=0	G
Offspring outcome:  Emotional problems (not including SRT/SRB/SA/complete d suicide) <sup>3</sup>	Schizophrenia	Mother	Maternal schizophrenia is significantly related to children's internalizing problems. Weighted mean effect size ( <i>r</i> ) 0.11 (95% CI 0.04-0.17) <i>Q<sub>w</sub></i> 21.84*	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=6 <sup>2</sup>			C&G <sub>3</sub>
		Father	Paternal schizophrenia is related to children's internalizing problems. Weighted mean effect size ( <i>r</i> ) 0.02 (95% CI -0.07-0.11) <i>Q<sub>w</sub></i> 0.23	Details of the exact comparison groups were not given in this review <sup>4</sup>			N=3 <sup>2</sup>	C&G <sub>3</sub>
	Bipolar	Mother	Maternal bipolar affective disorder is related to children's internalizing problems. Weighted mean effect size ( <i>r</i> ) 0.03 (95% CI -0.09 -0.15) <i>Q<sub>w</sub></i> 15.28*	Details of the exact comparison groups were not given in this review <sup>4</sup>			N=4 <sup>2</sup>	C&G <sub>3</sub>
		Father	NK	NA	NA	NA	NA	None



Offspring outcome:  Emotional problems (not including SRT/SRB/SA/complete d suicide) <sup>3</sup>		Parent	Significant differences in the CBCL (parent rating) scores for offspring internalizing disorders between the group of offspring with a parent with bipolar/schizoaffective disorder and the group of offspring with parents with no mental disorder. (SMD = 0.73, SE = 0.27, p < 0.01)	Offspring of mentally well parents	N=3 <sup>2</sup> Wilde Meyer and Bleichert Salloum and Thase			L
	Parental mental disorder: Depression	Mother	‘More problems in emotional regulation’  Maternal depression is significantly related to children’s internalizing problems. Weighted mean effect size ( <i>r</i> ) 0.16 (CI 0.15-0.17) <i>Q<sub>w</sub></i> 255.64*  Maternal depression more strongly related to children’s internalizing problems than paternal depression ( <i>g</i> =0.02, <i>p</i> <.05)	Offspring of mothers without depression  Details of the exact comparison groups were not given in this review <sup>4</sup>  Offspring of fathers with depression	N=2 Joorman Silk  N=78 <sup>2</sup>  N=109 <sup>2,5</sup>	N=0	N=0	M  C&G <sub>3</sub>  C&G <sub>3</sub>
		Father	Paternal depression is significantly related to children’s internalising problems. Weighted mean effect size ( <i>r</i> ) 0.14 (CI 0.12-0.16) <i>Q<sub>w</sub></i> 79.29*	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=31 <sup>2</sup>			C&G <sub>3</sub>
	Parental mental disorder: Personality disorder (EUPD unless specified otherwise)	Mother	Maternal anti-social PD is significantly related to children’s internalising problems. Weighted mean effect size ( <i>r</i> ) 0.10 (CI 0.05-0.15) <i>Q<sub>w</sub></i> 21.71*  “Significantly increased ‘emotional problems’ in adolescents of mothers with BPD”/EUPD compared to adolescents in the comparison group	Details of the exact comparison groups were not given in this review <sup>4</sup>  Offspring of mothers with depression or well mothers	N=4 <sup>2</sup>  N=1 Barnow 2006	N=0	N=0	C&G <sub>3</sub>  E

Offspring outcome:  Emotional problems (not including SRT/SRB/SA/complete suicide) <sup>3</sup>	Parental mental disorder: Personality disorder (EUPD unless specified otherwise)	Parental gender: Mother	‘Association’ with offspring insecure attachment style	Offspring of well mothers n=1 Offspring of mothers with depression n=2	N=5 Hobson et al 2005 Herr Abela	N=0	N=0	N=3 in E,P
				of mothers without EUPD n=1 offspring of well mothers n=1	Gratz  Macfie and Swan			N=1 in E N=1 in P
			‘Significantly lower self-esteem’ (in 11-18 year olds) compared to offspring in the comparison group	Evidence for: Offspring of mothers with depression, cluster C PD or well mothers Evidence against:	N=1 Barnow 2006	N=1	N=0	E
			‘Significant association’ with offspring self-criticism but not with lower self esteem	offspring of mothers with depression		Abela		E, P
			‘Significantly more parents’ (78% mothers) with EUPD had offspring with high total scores on Paediatric Symptom checklist <sup>2</sup>	Parents with other PD or well parents	N=1 Jellinek	N=0	N=0	E (not P)
			Mothers of sons (daughters not examined) with gender identity disorder significantly more likely to have EUPD than comparison group mothers	Mothers of sons without gender identity disorder	N=1 Marantz and Coates	N=0	N=0	E (not P)
			‘Significantly higher harm avoidance scores’		N=1	N=0	N=0	E, P

Offspring outcome:  Emotional problems (not including SRT/SRB/SA/complete d suicide) <sup>3</sup>	Parental mental disorder: Personality disorder (EUPD unless specified otherwise)	Parental gender: Mother	(adolescents) than comparison group offspring  Significant association with offspring emotional dysregulation          Significant association with offspring 'symptoms' (as described in the text) of EUPD (described as 'offspring outcome: psychopathology BPD' in Eyden et al's table)          Association between maternal EUPD and offspring unstable self-image	Offspring of well mothers or mothers with depression  Offspring of well mothers (n=1)/  No separate control group (n=1)/ offspring of mothers with depression or EUPD and depression or well mothers (n=1)/ offspring of 'comparison' mothers (n=1)  Offspring of comparison mothers (n=1)/ no control/comparison group described (n=3)  Offspring of mothers without EUPD  Offspring (sons) whose mother does not have EUPD	Barnow 2006  N=4 Macfie and Swan  Zalewski  White Macfie 2014  N=4  Cheng Barnow 2013 Conway Stepp  N=2 Macfie 2009  Marantz and Coates	N=0	N=0	E
						N=0	N=0	E
						N=0	N=0	E

Offspring outcome:  Emotional problems (not including SRT/SRB/SA/complete d suicide) <sup>3</sup>	Parental mental disorder: Personality disorder (EUPD unless specified otherwise)	Parental gender: Mother	Association between parental (mixed gender sample) EUPD traits and child emotional problems <sup>2</sup>	None described	N=0	N=1 Bertino	N=0	E,P
		Parental gender: Father	Significantly more parents (22% fathers) with EUPD had offspring with high total scores on Paediatric Symptom checklist <sup>2</sup>	Parents with other PD or well parents	N=1 Jellinek	N=0	N=0	P
			No significant association between parental (mixed gender sample) EUPD traits and child emotional problems <sup>2</sup>	None described	N=0	N=1 Bertino	N=0	E
	Parental mental disorder:  Psychopathology other/ NOS/ combined	Parental gender: Mother	Paternal anti-social PD is not significantly related to children's internalising problems. Weighted mean effect size ( <i>r</i> ) 0.05 (CI -0.04-0.15). <i>Q<sub>w</sub></i> 4.70	Details of the exact comparison groups were not given in this review <sup>4</sup>			N=4 <sup>2</sup>	C&G <sub>3</sub>
			The association between maternal mental disorder and child internalizing problems generated a population weighted mean effect size ( <i>r</i> ) 0.18 (95% CI 0.17-0.19) N= 94 studies N= 38,839 participants	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=94 <sup>2</sup>			C&G <sub>3</sub>
		Parental gender: Father	This was a significantly stronger association than that for fathers <i>p</i> <0.05	Offspring of fathers with mental disorder	N=153 <sup>2,5</sup>			C&G <sub>3</sub>
		Parental gender: Father	The association between paternal mental disorder and child internalizing problems generated a population weighted mean effect size ( <i>r</i> ) 0.14 (95% CI 0.13-0.15) N= 59 studies N= 25,186 participants	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=59 <sup>2</sup>			C&G <sub>3</sub>

Offspring outcome	Parental mental disorder	Parental gender	Offspring finding	Comparison group(s) in the study	Number of studies within the reviews, or (indicated by '2'), the number within a calculation (e.g. meta-analyses), which individually or overall, show evidence for/against/or are inconclusive, re the offspring finding			Rv Authors
					For	Against	Inconclusive	
Behavioural problems	Schizophrenia	Mother	Maternal schizophrenia is not significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.06 (95% CI -0.03-0.15) $Q_w$ 0.41	Details of the exact comparison groups were not given in this review <sup>4</sup>			N=3 <sup>2</sup>	C&G
		Father	Paternal schizophrenia is not significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.00 (95% CI -0.11-0.11) $Q_w$ 0.00	Details of the exact comparison groups were not given in this review <sup>4</sup>			N=1 <sup>2</sup>	C&G
	Bipolar	Mother	Significant differences in the CBCL (parent rating) scores for offspring externalizing disorders between the group of offspring with a parent with bipolar/schizoaffective disorder and the group of offspring with parents with no mental disorder (SMD = 0.81, SE = 0.20, $p < 0.001$ )  Maternal bipolar affective disorder is not significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.01 (95% CI -0.08-0.10) $Q_w$ 15.30*	Offspring of mentally well parents $n=3$  Details of the exact comparison groups were not given in this review <sup>4</sup>	N=3 <sup>2</sup> Wilde Meyer and Blechert Salloum and Thase	N=0	N=0  N=6 <sup>2</sup>	L  C&G
		Father	Significant differences in the CBCL (parent rating) scores for offspring externalizing disorders between the group of offspring with a parent with bipolar/schizoaffective disorder	Offspring of mentally well parents $n=3$	N=3 <sup>2</sup> Wilde Meyer and Blechert	N=0	N=0	L

Offspring outcome: Behavioural problems	Parental mental disorder: Bipolar		and the group of offspring with parents with no mental disorder (SMD = 0.81, SE = 0.20, $p < 0.001$ )  Paternal bipolar affective disorder is not significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) -0.13 (95% CI -0.27-0.01) $Q_w$ 0.12	Details of the exact comparison groups were not given in this review <sup>4</sup>	Salloum and Thase		N=2 <sup>2</sup>	C&G
	Depression	Mother	Maternal depression is significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.14 (95% CI 0.13-0.15) $Q_w$ 223.90*	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=79 <sup>2</sup>			C&G
		Father	Paternal depression is significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.10 (95% CI 0.06-0.13) $Q_w$ 53.44*	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=26 <sup>2</sup>			C&G
	Personality disorder	Mother	Significantly higher rates of behavioural problems  Maternal anti-social PD is significantly related to children's externalizing problems. Weighted mean effect size ( $r$ ) 0.13 (95% CI 0.09-.017) $Q_w$ 23.51*	Offspring of mother with another PD n=1/ Offspring of well mothers or mothers with depression n=1/ None described n=1/ Offspring of parent with another PD or well parent n=1  Details of the exact comparison groups were not given in this review <sup>4</sup>	N=4 Weiss  Barnow 2006 Bertino  Jellinek  N=10 <sup>2</sup>	N=0	N=0	E, P (n=2)  E (n=2)  C&G

Offspring outcome: Behavioural problems		Father	Paternal anti-social PD is significantly related to children's externalizing problems. Weighted mean effect size ( <i>r</i> ) 0.19 (95% CI 0.14-0.25) $Q_w$ 18.23*	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=9 <sup>2</sup>			C&G
	Parental psychopathology other/ NOS/ combined	Mother	The association between maternal mental disorder and child externalizing problems generated a population weighted mean effect size ( <i>r</i> ) 0.17 (95% CI 0.16-0.18) N=90 studies N=27,199 participants	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=90 <sup>2</sup>			C&G
		Father	The association between paternal mental disorder and child externalizing problems generated a population weighted mean effect size ( <i>r</i> ) 0.16 (95% CI 0.15-0.18) N=56 studies N= 14,729 participants	Details of the exact comparison groups were not given in this review <sup>4</sup>	N=56 <sup>2</sup>			C&G
Offspring outcome: Cognitive problems	Schizophrenia	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Bipolar	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Depression	Mother	Offspring of depressed mothers have more: - difficulty recognising positive bases - focus more on negative stimuli - decreased flexibility concerning their focus of attention	Offspring of mother without depression (n=2)	N=2 Joorman Silk et al 2006	N=0	N=0	M
		Father	NK	NA	NA	NA	NA	None
	Personality disorder	Mother	Significantly higher scores on the social problem scale (adolescents)	Offspring of mothers with depression, cluster C PD, or well mothers (n=1)	N=4 Barnow 2006	N=0	N=0	E, P
			Poorer theory of mind (pre-school) Significantly poorer labelling of emotions	Offspring of well mothers (n=1)	Schacht			E, P

Offspring outcome: Cognitive problems	Parental mental disorder: Personality disorder	Parental gender: Mother	‘Significantly poorer self-representations (incongruent and shameful)’	Offspring of well mothers	Macfie and Swan			E, P
			Significant association with decreased self-perception of social acceptability and ability to make friends	Offspring of mothers with depression	Herr			E, P
		Father	NK	NA	NA	NA	NA	None
	Parental psychopathology other/ NOS/ combined	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
Social problems	Schizophrenia	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Bipolar	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Depression	Mother	NK	NA	NA	NA	NA	None
		Father	NK	NA	NA	NA	NA	None
	Personality disorder	Mother	Children of mothers with EUPD were significantly more likely than comparison-group children to -experience changes in household composition and/or school, - experience more non-maternal care, -to ‘witness’ more violence and/or parental suicide attempts (24% of the children (average age 11-years) had witnessed a maternal attempt and 19% a paternal attempt) - experience verbal, and/or physical abuse - witness violence	Offspring of mothers with other personality disorders	N=1 Feldman	N=0	N=0	E, P



Offspring outcome: Social problems	Parental mental disorder: Personality disorder	Parental gender: Mother	Children and adolescents experienced 'higher general impairment in areas of home, school and social life'  Higher rate of single parenthood in mothers with EUPD	Offspring of mothers with other personality disorders	N=1 Weiss 1996	N=0	N=0	E
				Offspring of mothers with depression or cluster C PD or well mothers (n=1)/ offspring of well mothers (n=1)	N=2 Barnow 2006 Crittenden	N=0	N=0	P
	Parental psychopathology other/ NOS/ combined	Father	NK	NA	NA	NA	NA	NA
		Mother	NK	NA	NA	NA	NA	NA
		Father	NK	NA	NA	NA	NA	NA

<sup>1</sup> The Goodday et al review provided supplementary online figures showing the odds ratios and confidence intervals for the individual studies. The odds ratios could be ascertained precisely by hovering over the box on the figure, but the confidence intervals could only be approximated. We have therefore included the odds ratios but have not tried to approximate the confidence intervals beyond whether they crossed the line of no effect and therefore do not represent a significant finding.

<sup>2</sup> This is the number of studies in the meta-analysis/ other calculation, and not the total number which individually are for/ against/ inconclusive with regards to a finding. For findings from meta-analyses which were not showing a significant association, whether they were considered inconclusive or considered to show evidence against a finding, was decided by the current authors based on assessment of the effect size, the confidence interval, the sample size and the homogeneity of the samples involved. Where the number of studies in one column is the total number included in an analysis, and we are unable to discern how many of those studies individually supported (or did not support) a finding, we have not indicated numbers of studies in the other columns, for that particular calculation, as we do not know.

<sup>3</sup> Connell and Goodman are included here, but the offspring within the samples may have experienced some suicide related behaviours as part of a depressive episode or as sub diagnostic threshold presentations of depression.

<sup>4</sup> Although the individual studies' comparison groups were not detailed, by obtaining some (n=5) of the original papers, we can advise that comparison groups were various, with some comparing offspring with internalising problems, with healthy offspring, and then examining their parents for psychopathology, whilst others compared children of mentally unwell/disordered mothers/fathers to children of mothers/fathers who had a different mental illness/disorder, and/or children of mothers who were mentally well.

<sup>5</sup> The total number of studies in these analyses were not presented within the Connell and Goodman review, so we have calculated this number by adding together the number of studies which were included in the analysis of the relationship between the maternal pathology and the child internalising/externalising behaviour and the number of studies which were included in the analysis of the relationship between the paternal pathology and the child internalising/externalising behaviour.

Explanatory notes:

ASPD= antisocial personality disorder

CI = confidence interval

EUPD= Emotionally unstable personality disorder

NA= not applicable

NK= not known from the information presented in the reviews

NOS= not otherwise specified

OR = odds ratio

Psychopathology combined = this refers to analyses/studies where the parental sample includes a number of different diagnoses across the parents, so some of the parents may have had depression whilst others had schizophrenia, for example.

Psychopathology “other”: This refers to any psychopathology that would be relevant to our population of interest such as completed suicide. It does not encompass diagnoses which were explicitly excluded in the inclusion/exclusion criteria, such as alcohol use disorder(s) without comorbid major mental disorder.

PD= personality disorder

$Q_w$ = This is the within group homogeneity estimate provided by Connell and Goodman. If this is significant ( $p < 0.05$ ), indicated by an \*, this shows that this group of effect sizes is not homogenous.

Review authors: C&G = Connell and Goodman, R=Rasic et al, L=Lau et al, P=Petfield et al, E=Eyden et al, M=Mendes et al, G=Goodday et al.

Rv=review

SA= Suicide attempts are defined as any self-inflicted, potentially injurious behaviour with some intent to end one's life.

SE = Not further explained in Lau et al (2017). Thought to represent standard error.

SMD= Not further explained in Lau et al (2017). Thought to represent standardized mean difference.

SRB = suicide related behaviours, measures that were irrespective of suicidal intent were labelled as SRB

SRT=suicide related thoughts, defined by Goodday as any thoughts/ideas pertaining to ending one's life, suicide threats and plans

NB

- If the review included the paper, but the particular finding listed was not included in that review, then the review authors are not listed
- Only the first author of any individual study is given. The year is additionally stated if there is more than one study by the first author. Full references for those studies listed in this table, but which are not referenced in the main text can be obtained from the reviews indicated in the review authors column.



**Appendix C: Additional detail regarding the studies listed in supplementary table in Appendix B (listed in the order in which they appear in table in Appendix B), including the sample size, the study design and the risk of bias/quality assessment as performed by the review authors, where such detail was available in the citing reviews.**

Rv(s) <sup>1</sup>	First author (year of publication)	Sample size <sup>2</sup> and sample age where available	Study design	Quality/risk of bias (ROB) assessment of the study by the review(s)
G	Mittendorfer-Rutz et al (2008)	158840 (14440 cases)	Case-control	ROB: Serious <sup>3</sup>
G	Lewinsohn et al (2005)	711	Cohort	ROB: Moderate <sup>3</sup>
G	Klimes- Duggan et al (2008)	192	Cohort	ROB: Serious <sup>3</sup>
G	Weissman et al (1986)	220	Cross sectional	ROB: Serious <sup>3</sup>
G	Glowinski et al (2001)	1252	Cross sectional	ROB: Serious <sup>3</sup>
G	Reyes et al (2011)	691	Cohort	ROB: Moderate <sup>3</sup>
G	Santana et al (2015)	2942	Cross sectional	ROB: Serious <sup>3</sup>
G	Brent et al (2002)	299	Cross sectional	ROB: Serious <sup>3</sup>
G	Brent et al (2015)	701	Cohort	ROB: Serious <sup>3</sup>
G	Burke et al (2010)	449	Cross sectional	ROB: Serious <sup>3</sup>
E, P	Barnow et al (2006)	23 offspring of mothers with borderline personality disorder (BPD) 47 offspring of mothers with depression 31 offspring of mothers with cluster C personality disorder (PD) 156 offspring of healthy mothers 11–18 years	Case-control	7/9 E <sup>4</sup> 4/5 P <sup>5</sup>
G	King et al (2010)	352	Cohort	ROB: Serious <sup>3</sup>
G	An et al (2010)	2965	Cross sectional	ROB: Serious <sup>3</sup>
G	Lieb et al (2005)	933	Cohort	ROB: Moderate <sup>3</sup>
G	Min et al (2012)	707	Cross sectional	ROB: Serious <sup>3</sup>
G	Geulayov et al (2012)	6580	Cohort	ROB: Moderate <sup>3</sup>
G	Kuramoto et al (2010)	38440	Cohort	ROB: Serious <sup>3</sup>
G	Jakobsen et al (2011)	3465	Case-control	ROB: Serious <sup>3</sup>
G	Christiansen et al (2011)	403341	Case-control	ROB: Serious <sup>3</sup>
G	Niederkrotenthaler et al (2012)	18566 cases (matched up to 10 controls)	Case-control	ROB: Moderate <sup>3</sup>

Rv(s) <sup>1</sup>	First author (year of publication)	Sample size <sup>2</sup> and sample age where available	Study design	Quality/risk of bias (ROB) assessment of the study by the review(s)
G	Mortier et al (2017)	2042	Cohort	ROB: Serious <sup>3</sup>
G	Isohookana et al (2013)	508	Cross sectional	ROB: Critical <sup>3</sup>
G	Mercy et al (2001)	666	Case-control	ROB: Serious <sup>3</sup>
G	Ljung et al (2013)	235,395	Case-control	ROB: Moderate <sup>3</sup>
G	Agerbo et al (2002)	25296 (496 cases)	Case-control	ROB: Moderate <sup>3</sup>
G	Cheng et al (2014)	2000 (500 cases)	Case-control	ROB: Moderate <sup>3</sup>
L	Wilde et al (2014)	These three papers were used to identify 145 high-risk and 148 control offspring, which were then analysed as a single group	Not stated (from the reference this appears to be a meta-analysis)	ROB/quality assessment was not performed by Lau et al for these papers as far as the current authors can ascertain
L	Meyer and Blechert (2005)		Not stated	
L	Salloum and Thase (2000)		Not stated	
M	Joorman et al (2007)	41	Cross-sectional	20/24 <sup>6</sup>
M	Silk et al (2006)	78	Longitudinal	22/24 <sup>6</sup>
E, P	Hobson et al (2005)	32 infants: 10 of mothers with BPD 22 of mothers with no psychiatric disorder (12 months: 47–57 weeks)	Case-control	8/9 E <sup>4</sup> 4.4/5 P <sup>5</sup>
E, P	Herr et al (2008)	110 youths with current or past diagnosis of major depressive disorder (MDD) or dysthymic disorder (DD) 15 years	Cross sectional	9/10 E <sup>4</sup> 4.2/5 P <sup>5</sup>
E, P	Abela et al (2005)	120 children of parent with MDD 20 children of parents with MDD/BPD 6–14 years	Case-control	7/9 E <sup>4</sup> 3.6/5 P <sup>5</sup>
E, P	Gratz et al (2014)	23 infants of mothers with BPD (mean 17.4 months) 78 infants of mothers without BPD (mean 16.2 months) 12–23 months	Case-control	7/9 E <sup>4</sup> 4.4/5 P <sup>5</sup>

Rv(s) <sup>1</sup>	First author (year of publication)	Sample size <sup>2</sup> and sample age where available	Study design	Quality/risk of bias (ROB) assessment of the study by the review(s)
P	Macfie and Swan (2009) <sup>7</sup>	30 children of mothers with BPD 30 children of healthy mothers Ages 4-7 years	Case-control	4.4/5 P <sup>5</sup>
E	Jellinek et al (1991)	100 children of parents with affective disorders 351 children of parents with no disorder Interview: 19 children above PCS <sup>8</sup> cut off (6 of mothers with BPD) 18 children below PCS <sup>8</sup> cut off 6–12 years	Cross sectional	8/10 E <sup>4</sup>
E	Marantz and Coates (1991)	16 boys with gender identity disorder (GID) 17 boys without GID 8 years	Case-control	7/9 E <sup>4</sup>
E	Zalewski et al (2015)	1598 adolescent girls ages 15-17 years	Cross sectional from cohort	8/10 E <sup>4</sup>
E, P	White et al (2011)	87 infants. Mean age 3.5 months	Case-control	8/9 E <sup>4,9</sup> 4.2/5 P <sup>5</sup>
E	Macfie et al (2014)	31 children of mothers with BPD 31 children of comparison mothers 4–7 years	Case-control	8/9 E <sup>4</sup>
E	Barnow et al (2013)	323 offspring T0 15 years T1 20 years	Cohort (2 time points)	7/9 E <sup>4</sup>
E	Conway et al (2015)	T1 815 offspring age 15 T2 700 offspring age 20	Cohort (2 time points)	7/9 E <sup>4</sup>

Rv(s) <sup>1</sup>	First author (year of publication)	Sample size <sup>2</sup> and sample age where available	Study design	Quality/risk of bias (ROB) assessment of the study by the review(s)
E	Stepp et al (2013)	T1: 360 adolescents with depressive disorder, 284 with non-mood disorders, 457 no psychiatric history; 14–18 years T2: 1507 T1 adolescents 15–19 years T3: 644 adolescents history psychiatric illness 457 without, 24 years T4: 816 T3 participants, 30 years	Cohort longitudinal	7/9 E <sup>4</sup>
E	Macfie (2009)	30 children of mothers with BPD 30 children of mothers without BPD Aged 4-7 years	Case-control	8/9 E <sup>4</sup>
E	Bertino et al (2012)	30 children 4–8 years 29 adolescent 12–18 years	Cross sectional	7/10 E <sup>4</sup>
E, P	Weiss et al (1996)	21 children of mothers with BPD 23 children of mothers with non-borderline PD 4+ years, mean BPD group: 12 years, control group: 9.5 years	Case-control	7/9 E <sup>4</sup> 4/5 P <sup>5</sup>
E, P	Schacht et al (2013)	39 children ages 3-5 years	Case-control	9/9 E <sup>4</sup> 4.2/5 P <sup>5</sup>
E, P	Feldman et al (1995)	21 children of mothers with BPD 4+ years (mean 12 years) 23 of mothers with other PDs 4+ years (mean 9.6 years)	Case-control	8/9 E <sup>4</sup> 3.8/5 P <sup>5</sup>
E, P	Crittenden and Newman (2010)	32 infants ages 3-36 months	Case-control	8/9 E <sup>4</sup> 3.8/5 P <sup>5</sup>



[1] Rv(s): this column indicates the review(s) which featured a particular study. Reviews are denoted by the first letter of the first author of the review, hence G= Goodday et al, E= Eyden et al, P= Petfield et al, L= Lau et al, M= Mendes et al. Where more than one review featured a study and where each provided a quality rating, the same review author abbreviations are used to indicate who reported each quality rating.

[2] Sample size is given as reported in the relevant reviews, hence the differing level of detail. Often the sample size indicates the overall sample size rather than the number of offspring or the number of participants which feature in any particular finding/calculation. However, where detail about the number of offspring is given by the review this is shown in the table. The information relating to papers which are included in both the Eyden et al and the Petfield et al reviews, is taken from the Eyden et al review.

[3] Goodday: Risk of bias (ROB) was systematically assessed using criteria from the Cochrane Risk of Bias Assessment Tool: for Non-Randomised Studies of Interventions (ACROBAT-NRSI) (Sterne et al. 2014)<sup>1</sup>. Each study was assigned a rating of one of low, moderate, serious or critical risk of bias.

[4] Eyden: The quality of each study was assessed using the Newcastle–Ottawa Scale (Wells et al., 2000)<sup>2</sup>.

[5] Petfield: the quality assessment was based on The Strengthening the Reporting of Observational studies in Epidemiology (STROBE) checklist<sup>3</sup>.

[6] Mendes: Assessment of the methodological quality of the studies was based on a modification of the checklist developed by Mirza and Jenkins (2004)<sup>4</sup>.

[7] Macfie and Swan does also feature in the Eyden et al review and we have included their findings in our results, however Eyden et al[5] do not include this in their table of included studies and thus provide no quality assessment nor details re participants etc. These details are thus taken solely from Petfield et al.

[8] Eyden et al have written ‘PCS’ in their table, but the only close explanatory note is for ‘PSC’ which refers to the Pediatric Symptom Checklist. Given the main text of the Eyden et al review discusses this paper’s findings in relation to the Pediatric Symptom Checklist, we assume that this is the instrument referred to.

[9] White et al is listed in the supplementary table from Eyden et al as being from 2014, however the reference in the main text refers to White et al 2011 and we have therefore concluded that this is most likely a typo in the supplementary material and attributed the quality rating from Eyden et al to this paper.

References relating to the table in this appendix:

<sup>1</sup>Sterne JA, Higgins JP, Reeves BC. On behalf of the development group for ACROBAT-NRSI, 2014. A Cochrane Risk of Bias Assessment Tool: for Non-Randomized Studies of Interventions (ACROBAT-NRSI), Version 1.0. 0.

<sup>2</sup>Wells GA, Shea B, O Connell D, et al. The Newcastle Ottawa Scale (NOS) for assessing the quality of nonrandomized studies in meta-analyses. 2014. Unpublished manuscript.  
[http://www.ohri.ca/programs/clinical\\_epidemiology/oxford.asp](http://www.ohri.ca/programs/clinical_epidemiology/oxford.asp)

<sup>3</sup>Von Elm E, Altman DG, Egger M, et al. The strengthening the reporting of observational studies in epidemiology [STROBE] statement: guidelines for reporting observational studies. *Gac Sanit* 2008; 22:144–50.

<sup>4</sup>Mirza I, Jenkins R. Risk factors, prevalence, and treatment of anxiety and depressive disorders in Pakistan: systematic review. *BMJ*. 2004; 328:794.

## **Appendix D: Data collection checklist**

D.O.B. \_\_\_\_\_

Coding No: \_\_\_\_\_

Key: If answered 'other' please specify      999 = Not applicable      99 = Data not available

<b>Date of birth</b>	
<b>Ethnicity</b> 0=white, 1=black caribbean, 2=black african, 3=Black other, 4=Indian subcontinent, 5=other Asian, 6=mixed, 9=don't know, 7=other (specify)	
<b>Place of birth</b> 0=UK, 1=other European, 2=other, 9=DK	
<b>Date of (age on) first ever admission to medium security</b> <i>Note: estimate date of admission as 30 06 of the year calculated from age on admission if actual date not known.</i>	
<b>Date of current admission to Caswell Clinic</b>	
<b>Process stage</b> 0=civil patient, no index criminal charges or convictions 1=pre-trial 2=convicted of an index, relevant offence	
<b>Place from where admitted</b> 0=community, 1=NHS general hospital unit, 2=NHS/independent sector medium secure hospital unit, 3=high security hospital unit, 4=prison, 5=other	
<b>Nature of current legal detention in Caswell Clinic (legal status)</b> 0=none 1=civil 2=MHA remand provisions/pre-trial prison transfer 3=unrestricted hospital order 4=restricted hospital order 5=unrestricted prison transfer (sentenced) 6= restricted prison transfer (sentenced) 7=other (specify)	
<b>Date of discharge from Caswell (88 88 8888 if not applicable)</b>	
<b>Legal status immediately after discharge (code as above)</b>	
<b>MHA classification at discharge (code as above)</b>	
<b>Location immediately after discharge</b> 0=died, 1=independent community, 2=with family, 3=other supported community, 4=health service open, 5=health service low security, 6=health service medium security, 7=health service high security, 8=prison, 9=don't know, 10=other (specify)	
<b>PERSONAL HISTORY</b>	
<b>Employment status when first detained</b> <i>unemployed = 0, employed = 1, retired = 2, student = 3, other = 4, unable to work due to external/ physical/ environmental factors(including hospitalisation/imprisonment = 5, never employed = 6)</i>	
<b>Nature and number of previous occupations – Give details:</b>	
<b>Specify longest continuous period of employment to the nearest six months</b>	
<b>Living arrangements at beginning of current period of detention/time of index offence (living alone = 0, living with partner = 1, living with another person outside native family, = 2, living with a parent = 3 living with another family member, 4=living in a hostel/supported accommodation, 5=hospital resident, 6=prison resident, 7=other)</b>	

<b>Relationship/ marital status on admission</b> ( <i>single = 0, married = 1, divorced = 2, separated = 3, civil partnership = 4, other = 5, undisclosed = 6, widowed = 7</i> )				
<b>MENTAL HEALTH HISTORY</b>				
<b>Previous treatment in psychiatric services</b> (treat ratings as a hierarchy) 0=never, 1=out-patient only, 2=resident at least once in a general psychiatric unit, 3=resident at least once in a specialist medium or high secure hospital unit				
<b>Age at first record of psychiatric service use</b>				
<b>Ever seen by child psychologist/psychiatrist</b> 0=no, 1=yes				
<b>Estimate total length of time spent as a psychiatric hospital inpatient to the nearest six months</b>				
<b>CRIMINAL HISTORY</b>				
<b>Most recent conviction (index)</b>	Yes		Yes	
<i>Homicide</i>		<i>Criminal Damage</i>		
<i>Attempted murder/GBH</i>		<i>Theft/burglary</i>		
<i>ABH/threats/weapons</i>		<i>Forgery/deception</i>		
<i>Sexual offences</i>		<i>Alcohol/drug related</i>		
<i>Robbery</i>		<i>Vagrancy</i>		
<i>Firearms offences</i>		<i>Kidnapping</i>		
<i>Arson</i>		<i>Harassment</i>		
<i>Other</i>		<i>Affray</i>		
Other – Give Details:  <b>Rate seriousness of the index offence/act:</b>  <i>0 – Non-violent</i> <i>1 – Low violence: Threatened violence, but without weapon in hand; property damage of personal relevance to the victim; made body contact, but no injury</i> <i>2 – Moderate violence: actual physical violence to the individual which required some basic first aid; credible threat with weapon in hand</i> <i>3 – Moderately serious violence: severely violent episode which required medical treatment</i> <i>4 – Serious violence: life threatened or taken.</i> <i>9 – Unrateable (excludes doubts between categories when the lower rating should be used)</i>				
<b>Age at first offence:</b>				
<b>Details of Most serious past offence:</b>				
<b>Victim of index offence/act:</b> Specify <b>Number of victims:</b> <b>Sex of victim:</b> Code: 1=female, 2=male <b>Age of victim:</b>				

1=0-11, 2=12-18, 3=18-70, 4=71+			
<b>Relationship to victim:</b> 0=none (stranger), 1=spouse/partner/lover; 2=parent, 3=other family, 4=friend/acquaintance, 5=official (hospital staff/police or similar), 6=other (specify) NB, where multiple victims, code sex, age and relationship for each			
<b>Violence/other incidents against staff members during current admission</b> 0=no, 1=yes			
<b>Violence/other incidents involving staff members during most immediate previous admission</b> 0=no 1=yes			
<b>Prior offences involving children:</b> 0=no, 1=yes			
<b>BEHAVIOURAL DISORDER WHICH HAS NOT LED TO CRIMINAL CHARGES</b>	Yes		Yes
<i>Violence</i>		<i>Self-injury</i>	
<i>Fire setting</i>		<i>Suicidal</i>	
<i>Sexual offending behaviour</i>		<i>Other</i>	
<i>Absconding</i>			
<b>Life time seriousness of violence up to but not including the index offence</b>  <b>0. No violence:</b> no violence recorded or self-reported.  <b>1. Aggressive and threatening behaviour, minor damage to property:</b> offences such as breach of peace, criminal damage, threats to kill are included. Verbal threats and verbal aggression and racial abuse, slamming or hitting doors, smashing or throwing items, hostile and intimidating behaviour are included.  <b>2. Personal assault against another without lasting damage/serious property damage:</b> common assault, affray and ABH damage to property due to arson without intention to endanger life and sexual offences with violence but not rape are included. Violence includes pushing, punching, slapping, kicking, hitting, and head butting without lasting damage to the body, causing damage such as soreness, lacerations, swelling, bruises or none.  <b>3. Personal injury requiring medical treatment, health threatened or residual damage:</b> It includes offences such malicious wounding, wounding with intent causing GBH and, arson with intention of endangering others' lives. Violence includes pushing, punching, slapping, kicking, hitting, and head butting with lasting damage to the body, causing injuries might including bone fractures, permanent dysfunction, organ failure and/or anything requiring surgical intervention); serious sexual violence, e.g. rape; serious property damage such as destruction of a room/building by fire; damage by fire if this knowingly threatened life); threats to kill if made with a drawn weapon, attempt to strangle or repeated and of explicitly serious violence.  <b>4. Life taken or seriously in danger:</b> includes offences such as homicide/murder/manslaughter and attempt of murder.  <div style="text-align: center; margin-top: 20px;"> <div style="border: 1px solid black; width: 40px; height: 40px; display: inline-block;"></div> </div>			

<b>CRIMINAL HISTORY BEFORE (AND EXCLUDING) THE INDEX OFFENCE 0=no, 1= at least once; 2=at least twice or more</b>	Code		Code
<i>Major Violence</i>		<i>Alcohol related</i>	
<i>Minor Violence</i>		<i>Drug related</i>	
<i>Sexual offences</i>		<i>Firearms</i>	
<i>Arson</i>		<i>Robbery</i>	
<i>Criminal damage</i>		<i>Other</i>	
<i>Acquisitive offence</i>			

<b>INSTITUTIONAL HISTORY</b>	Yes		Yes
<i>Children's home/foster care</i>		<i>Prison</i>	
<i>Other non-parental care</i>		<i>Hostel</i>	
<i>Approved school</i>		<i>Previous psychiatric admission</i>	
<i>Borstal/YOI</i>		<i>Other</i>	

<b>MOST RECENT DIAGNOSIS AXIS I (use ICD-10 code)</b>	Yes		Yes
<i>Schizophrenia</i>		<i>Drug abuse</i>	
<i>Schizoaffective</i>		<i>Phobia</i>	
<i>Paranoid psychosis/schizophrenia</i>		<i>Anxiety/Panic</i>	
<i>Unspecified psychosis</i>		<i>Obsessive/compulsive</i>	
<i>Mania/hypomania</i>		<i>Epilepsy</i>	
<i>Depression</i>		<i>Organic brain syndrome</i>	
<i>EtOH dependency</i>		<i>Other</i>	
<i>EtOH abuse</i>		<i>IQ =</i>	
<i>Drug dependency</i>			

<b>AXIS II</b>	Yes		Yes
<i>Anti-social</i>		<i>Dependent</i>	
<i>Borderline</i>		<i>Histrionic</i>	
<i>Paranoid</i>		<i>Obsessive/compulsive</i>	
<i>Schizoid</i>		<i>Avoidant</i>	
<i>Schizotypal</i>		<i>Other P.D = 1°</i>	

**Evidence of disorder relating to Index Offence:**  
0=no, 1=yes

**Change in diagnosis since first admission to medium secure**  
0=no, 1=yes  
specify

<b>Change in diagnosis during current admission to Caswell</b> 0=no, 1=yes specify			
<b>Experience of trauma</b> For each, code 0=no, 1=yes in childhood only (<16years), 2=yes in adulthood only (>16years), 3=yes both in childhood and adulthood			
<b>Trauma</b>	<b>Code</b>	<b>Comments (family/non-family perpetrator)</b>	
<i>Rape</i>			
<i>Sexual abuse</i>			
<i>Physical abuse</i>			
<i>Emotional abuse</i>			
<i>Inter-parental Violence</i>			
<i>Parental separation (age etc.)</i>			
<b>Age at first trauma</b>			
<b>Age at most recent documented trauma</b>			
<b>Indication of level of recording of information about previous trauma</b> 0=no trauma recorded 1=all records of trauma reflect patient's self-report alone 2=at least one episode of self-reported trauma has accompanying independent verification of some kind 3=all records of trauma are self-reported <u>and</u> have independent verification 4=all records of trauma come from an informant and the patient has never reported this 5=indications that staff suspect a trauma history, but none has been established by patient self-report or other report 6=impossible to judge from the records where the information comes from			
<b>Patient's relationship with own parents</b> <i><b>Quality</b></i> 0=generally good, 1=some difficulties, 2=harsh and inconsistent discipline, 3=at least one abusive parent <i><b>Presence</b></i> 0=with both parents throughout childhood, 1=parental separation before age 11, 2=parental separation when aged 11-18, parental separation/absenteeism, details not known <i><b>Notes:</b></i>			
<b>Is there any current or previous legal case against a parent for abuse of a child?</b> 0=no, 1=yes Give details:			
<b>Record of parental mental health</b> 0=no problems recorded, 1=only maternal mental disorder (md), 2=only paternal md, 3=both parents had md, <b>Other family history of md</b> 0=no, 1=yes			



Notes:	
<b>Record of parental substance misuse</b> 0=no problems recorded, 1=only maternal substance misuse (sm), 2=only paternal sm, 3=both parents had sm, <b>Other family history of sm</b> 0=no, 1=yes Notes:	
<b>Record of parental criminal record (CR)</b> 0=no problems recorded, 1=only maternal cr, 2=only paternal cr, 3=both parents had cr, <b>Other family history of cr</b> 0=no, 1=yes	
<b>PATIENT'S RELATIONSHIP HISTORY</b>	
(excluding current partnership, documented above)	
<b>Sexual Orientation</b>	
<i>Heterosexual = 1, Homosexual = 2, Bisexual = 3</i>	
<b>Number of previous sexual partners</b>	
<b>Number of stable relationships (6 months or more)</b>	
Evidence of discussion of <b>contraception</b> this admission <i>yes = 1, no = 0</i>	
Patient having some form of current contraception <i>yes = 1, no = 0</i>	
<b>PATIENT'S CHILDREN</b>	
Evidence of being formally asked whether or not s/he has a child now <i>yes = 1, no = 0</i>	
Evidence of being formally asked whether or not s/he has ever previously had a child <i>yes = 1, no = 0</i>	
Evidence of being formally asked whether or not s/he had expected to have a child but the pregnancy failed <i>yes = 1, no = 0</i>	
Does patient have children? <i>(yes = 1, no = 0)</i>	
<b>IF NO,</b> Has the clinical team explored that any further? 0=no, 1=yes Has the clinical team asked whether the patient is content with his/her childless status? 0=no, 1=yes	
<b>IF YES,</b> number of biological children	
Number of other children in a relationship with the patient at the time of admission <i>(please specify nature of relationship)</i> Not biologically related (e.g. stepchildren)	

Biologically related but as grandchild, nephew, niece etc. (specify)	
Number of children who are of dependent age at the time of the parent's current admission	
Number of children who are of dependent age and for whom the parent has parental responsibility in the 12 months prior to his/her admission	
Number of children who are of dependent age at the time of the parent's admission and for whom the parent has not had parental responsibility in the 12 months before his/her admission	
Number of pregnancies ( <i>women only</i> )	
Total number of children born ( <i>not miscarriages</i> )	
Nature of unsuccessful pregnancies	
<b>CODE FOLLOWING FOR EACH CHILD SEPERATELY</b>	
Child 1 ( <i>Biological = 1, Other = 2</i> ) if 'other' state relationship	
Child 1 Gender ( <i>Male = 1, Female = 2</i> )	
Child 1 D.O.B (if known – current age if not)	
Child 1 alive at last report ( <i>yes = 1, no = 2</i> )	
If no, child 1 cause of death ( <i>obstetric = 1, illness = 2, accident = 3, homicide = 4</i> )	
Child 1 date of last contact (phone/face to face only)	
Ever been full time caretaker of child 1 ( <i>yes = 1, no = 0</i> )	
Child 1 nature of parental responsibility 12 months prior to Caswell/ I.O. ( <i>none = 0, sole parental responsibility = 1, joint parental responsibility = 2</i> )	
Child 1 nature of contact 12 months prior to Caswell/ I.O. ( <i>none = 0, letterbox = 1, telephone = 2, face to face = 3, other = 4 [e.g. social media]</i> )	
Child 1 permitted frequency of contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 1 actual frequency of contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 1 approximate length of actual contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, 1 hour or less = 1, 1-4 hours = 2, 5-12 hours = 3, continuous = 4</i> )	
Child 1 contact 12 months prior to Caswell/ I.O. ( <i>Supervised = 1, Unsupervised = 2</i> )	

Child 1 other parent ( <i>previous partner = 1, current partner = 2, other = 3</i> )	
Child 1 primary carer 12 months prior to Caswell/ I.O. ( <i>with mother = 1, with father = 2, other immediate relative = 3, other = 4</i> )	
Child 1 formal arrangement of care 12 months prior to Caswell/ I.O. ( <i>none = 0, custody order = 1, residential order = 2, adoption in procedure = 3, adopted = 4, PS order = 5, foster care = 6</i> )	
Child 1 nature of parental responsibility after admission ( <i>none = 0, sole parental responsibility = 1, joint parental responsibility = 2</i> )	
Child 1 nature of contact after admission ( <i>none = 0, letterbox = 1, telephone = 2, face to face = 3</i> )	
Child 1 permitted frequency of contact after admission ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 1 actual frequency of contact after admission ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 1 approximate length of actual contact after admission ( <i>no contact = 0, 1 hour or less = 1, 1-4 hours = 2, 5-12 hours = 3, continuous = 4</i> )	
Child 1 primary carer after admission ( <i>with mother = 1, with father = 2, other immediate relative = 3, other = 4</i> )	
Child 1 formal arrangement of care after admission ( <i>none = 0, custody order = 1, residential order = 2, adoption in procedure = 3, adopted = 4, PS order = 5, foster care = 6</i> )	
Child 1 reason for change in primary carer ( <i>I.O. = 1, parent left = 2, indirect harm to child = 3, parental MI = 4, prison = 5, deliberate harm to child = 6, other = 7</i> )	
Child 1 age when the patient ceased to be primary carer	
If never been primary carer, what is the reason for this? ( <i>I.O. = 1, parental mental illness = 2, Prison = 3, Relationship breakdown = 4, other = 5</i> )	
Child 1 nature of current supervision of contact ( <i>none = 0, other relative/ social worker always present = 1, Caswell staff or other always present = 2, other relative/ social worker always outside checking/ available = 3, Caswell staff or other always outside checking/available = 4</i> )	
If no contact with child 1, has an application been made for contact ( <i>yes = 1, no = 0</i> )	
An order against patient having contact with child 1 as a result of illness/offence ( <i>yes = 1, no = 0</i> )	
Child 1 any special needs ( <i>yes = 1, no = 0</i> ) if yes, give details	

Child 1 notes – indicators of qualities of parent/child relationship	
Child 2 ( <i>Biological = 1, Other = 2</i> ) if 'other' state relationship	
Child 2 Gender ( <i>Male = 1, Female = 2</i> )	
Child 2 D.O.B (if known – age if not)	
Child 2 alive at last report ( <i>yes = 1, no = 0</i> )	
Child 2 cause of death ( <i>obstetric = 1, illness = 2, accident = 3, homicide = 4</i> )	
Child 2 date of last contact (phone/face to face only)	
Ever been full time caretaker of child 1 ( <i>yes = 1, no = 0</i> )	
Child 2 nature of parental responsibility 12 months prior to Caswell/ I.O. ( <i>none = 0, sole parental responsibility = 1, joint parental responsibility = 2</i> )	
Child 2 nature of contact 12 months prior to Caswell/ I.O. ( <i>none = 0, letterbox = 1, telephone = 2, face to face = 3</i> )	
Child 2 permitted frequency of contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 2 actual frequency of contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 2 approximate length of actual contact 12 months prior to Caswell/ I.O. ( <i>no contact = 0, 1 hour or less = 1, 1-4 hours = 2, 5-12 hours = 3, continuous = 4</i> )	
Child 2 contact 12 months prior to Caswell/ I.O. ( <i>Supervised = 1, Unsupervised = 2</i> )	
Child 2 other parent (previous partner = 1, current partner = 2, other = 3)	
Child 2 primary carer 12 months prior to Caswell/ I.O. ( <i>with mother = 1, with father = 2, other immediate relative = 3, other = 4</i> )	
Child 2 formal arrangement of care 12 months prior to Caswell/ I.O. ( <i>none = 0, custody order = 1, residential order = 2, adoption in procedure = 3, adopted = 4, PS order = 5, foster care = 6</i> )	
Child 2 nature of parental responsibility after admission ( <i>none = 0, sole parental responsibility = 1, joint parental responsibility = 2</i> )	

Child 2 nature of contact after admission ( <i>none = 0, letterbox = 1, telephone = 2, face to face = 3</i> )	
Child 2 permitted frequency of contact after admission ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 2 actual frequency of contact after admission ( <i>no contact = 0, daily = 1, weekly = 2, monthly = 3, yearly = 4</i> )	
Child 2 approximate length of actual contact after admission ( <i>no contact = 0, 1 hour or less = 1, 1-4 hours = 2, 5-12 hours = 3, continuous = 4</i> )	
Child 2 primary carer after admission ( <i>with mother = 1, with father = 2, other immediate relative = , other = 4</i> )	
Child 2 formal arrangement of care after admission ( <i>none = 0, custody order = 1, residential order = 2, adoption in procedure = 3, adopted = 4, PS order = 5, foster care = 6</i> )	
Child 2 reason for change in primary carer ( <i>I.O. = 1, parent left = 2, indirect harm to child = 3, parental MI = 4, prison = 5, deliberate harm to child = 6, other = 7</i> )	
Child 2 age when the patient ceased to be primary carer	
If never been primary carer, what is the reason for this? ( <i>I.O. = 1, parental mental illness = 2, prison = 3, relationship breakdown = 4, other = 5</i> )	
Child 2 nature of current supervision of contact ( <i>none = 0, other relative/ social worker always present = , Caswell staff or other always present = 2, other relative/ social worker always outside checking/ available = 3, Caswell staff or other always outside checking/available = 4</i> )	
If no contact with child 2, has an application been made for contact ( <i>yes = 1, no = 0</i> )	
An order against patient having contact with child 2 as a result of illness/offence ( <i>yes = 1, no = 0</i> )	
Child 2 any special needs ( <i>yes = 1, no = 0</i> ) if yes, give details	
Child 2 notes - indicators of qualities of parent/child relationship	



## **Appendix E: Interview Schedule v0.1 (15.12.2017)**

### **INTERVIEW GUIDE**

**INTERVIEWER'S INITIALS:** \_\_\_\_\_ **PARTICIPANT'S ID:** \_\_\_\_\_  
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#### ***Introduction***

Interviewer introduces himself/herself and explains their role.

Interviewer checks that the participant has provided consent, signed the consent form, that they have a copy and that they are happy with their decision with regards to the interview being recorded [or not].

The participant is reminded that the interviewer has no role in the care and treatment of the participant's parent and that they are not in a position to give any information at all about the parent or to confirm or deny any beliefs that the child may have about the parent.

Interviewer assures participant that the interview is confidential within the research team, but reminds them that if they say anything which indicates that somebody, including the participant himself/herself, is at risk of serious harm, then they would have to pass that information, to someone else, to safely manage that risk.

Interviewer reminds the participant that they do not have to answer any question that they do not wish to and that they can ask for a break or to end the interview at any time.

Interviewer asks the participant whether they have any questions at this point or if they are happy to go ahead with the interview. If the interviewee is, and if the interview is to be audio recorded, then the interviewer will commence recording and pass the interviewee a card to read from giving their participant ID and a verbal confirmation of consent to have the interview recorded. If the interview is not to be recorded, then the interviewer will proceed to the main interview once any final questions from the participant have been answered.

#### **Main interview**

***Preliminary questions (to develop rapport – answers can be explored in more depth to this end if feels natural to do so)***

I wonder if I could start with a few questions about you?

Could I ask your age?

And who, if anyone, do you live with currently?

May I ask whether you're in a relationship currently (if not already evident)?

And may I ask, do you have any children (again, if not self-evident)?

Have you always lived in the UK?

If no, where else have you lived?

May I ask, at what age did you finish school?

And did you leave with qualifications?

Have you done any courses since school, like an apprenticeship, or at college, or university?

And are you in work at the moment?

If yes, - what sort of work do you do?

- is that full time or part time?

- and is that a temporary or permanent position?

If no, - have you worked previously?

Do you have any long term goals or plans?

- Interviewer can clarify if necessary. For example, in relation to education, work, family, travel or leisure?

### ***Transition question***

Can I confirm that it is/was your father/mother\* who is/was a patient in a secure\*\* hospital?

If from the reply here it is not evident, then a follow up question would be added to ascertain the nature of the relationship:

And can I ask, is this your birth mother/father?

If 'no', and the participant does not expand, ask 'could I ask how you would describe your relationship with your mother/father?'

Could I ask, how many admissions has your mother/father had to a secure hospital?

### ***Open interview section***

If the participant has indicated that there has been more than one admission add: 'it may be helpful to start with the first admission [you're aware of] and go from there, but don't worry if that isn't what feels easiest, what's important is that we hear about what is important to you, so please tell me about ***your experience*** of having your mother/father as a patient in a secure hospital.

If there has only been one admission then simply ask: 'Please tell me about ***your experience*** of having your mother/father as a patient in a secure or forensic hospital.'

Offer simple prompts and encouragement such as 'tell me more', 'that sounds difficult', 'how was that for you?' Or, 'can you explain that to me?' Or, 'are you sure there is nothing else you'd like to say about that?' Nonverbal cues will also be used, such as nodding, etc.

Once the participant has absolutely nothing to add, interviewer thanks the participant for sharing this.

### ***Semi-structured interview***

The interviewer moves on to the following semi-structured interview questions (only covering those areas which have not yet been answered or thoroughly explored).

Questions may be slightly modified or omitted to account for what has already been talked about.

#### **Detail around the parent's hospital admission(s)**

I wonder if I could ask some specific questions now?

If the participant has spoken about one parental admission only then ask the questions below, if not covered already. If the participant has referred to more than one admission, then the same questions apply, but start with the first admission and then progress chronologically (the timeline can be used if helpful).

- How old were you when your mother/father was [first/next] admitted to a/the secure hospital?
- Can you tell me about how you found out that your mother/father had been admitted to a secure hospital? Add prompts such as 'what was that like for you?'



- If it is still not clear, ask when they found out in relation to the time of the parent's admission? E.g. 'So how long after your mother/father was admitted did you find out where he/she was?'
- If there was a gap between the admission and the child finding out, ask 'so between the time they were admitted, and you finding out that's where they were, what was your understanding of where your mother/father was?'
- What did you know about **why** your mother/father had been admitted to a secure hospital?
  - o Did you feel adequately informed about what was happening and why?
  - o Did you feel adequately involved?
- And can I ask how was the time around your mother/father's admission, **for you**?
- Were there any **positive changes** that happened because your mother/father was a patient in a secure hospital?
  - o E.g. feeling safer, knowing your mother/father was safe/receiving treatment, moving house or school, living somewhere different etc.
- Do you feel that you've gained any particular **strengths** as a result of your experience of your mother/father being a patient in a secure hospital?
  - o E.g. maturity/independence/creativity/resourceful
- Were there any more **difficult changes** that happened because your mother/father was a patient in a secure hospital?
  - o E.g. not having contact with your mother/father, moving home or school, living with someone else, change in primary carer, changes in the mental health of the other parent/siblings, loss of income, worrying about people finding out etc.
- Do you feel that you've experienced any particular **problems** because your mother/father was in a secure hospital?
- Can I ask, did the **amount of contact** that you had with your mother/father change after their admission? Add prompts to get a good understanding of this.
- Did the **nature (phone/letter/face to face) of contact** that you had with your mother/father change after their admission? Explore further if, for example, contact was initially stopped after the parent's admission and then gradually reinstated.
- What did you **feel** about those changes (if any)?
- If not clear, ask 'did you/have you **visited** your mother/father in the secure hospital?'

- If no, ‘is that your **choice?**’ Explore further.
  - If yes, ask ‘can you tell me why that was?’
  - If no, ask ‘what has stopped you visiting him/her?’
- If yes, ‘what were your expectations before your first visit?’
- And, can you tell me what your **experience of visiting** was actually like?
- When you visited, what was your experience of the staff at the hospital?
- Did you feel safe there?
- Was anyone else **aware** of your mother/father being in a secure hospital?
  - If no, ‘was that your choice?’
    - If yes, ‘can I ask why?’
    - If appropriate, ask a follow up question specifically about ‘did you feel there was **stigma** around your mother/father’s situation?’
  - If yes, ‘can you tell me about your experience of this?’
- Sometimes when someone’s parent becomes unwell or things go wrong at home the children **feel responsible, or to blame**, even though it is not their fault. I wonder whether you ever had any feelings like that at all?
- Were you able to **talk to anyone** about your mother/father being in a secure hospital?
  - If yes, ‘who was this?’ ‘What was it like to talk to them?’
  - If no, ‘would you have liked to talk to someone?’
- Did you feel you would have liked any [other] **additional support** during this time?
  - If yes, what support would you have liked to have, ideally? Either from family/school/friends/ services (health and other).
  - Ask specifically, if not covered, whether **professionals** could have done anything to have improved things for you? If not mentioned, ‘and what about **health services** specifically?’
- If the admission referred to has come to an end, ask ‘could I ask how the experience of your mother/father being **discharged/transferred** from hospital was for you?’
  - E.g. ‘were you informed?’
  - Did you know where to and why?

- How did this discharge/transfer affect your relationship with your mother/father?
- Could anything have been done better, from your perspective?
- If the admission is ongoing ask ‘what would you like for you mother/father in the future, in terms of their progress beyond hospital?’

If the participant has indicated that their mother/father has only had one secure hospital admission, then the interviewer will move on to the next question. If there has been more than one parental secure hospital admission, then the above areas will be covered for the subsequent admissions, although this may not require asking every question verbatim, but rather broadly seeking some comparing and contrasting between the admissions.

- Some admissions may predate the participant’s birth, but if the participant has knowledge of them, then some basic dates and durations would be helpful, if known.

Have there been separations from other important people in your life because of your mother/father being in hospital?

If yes,

- Who was that from?
- Can you tell me a bit more about how that was for you? Ask further questions as proportionate to the significance of this separation to the participant.

#### Other separations

Have there been other types of separations from your mother/father? (e.g. prison/hospital/divorce/living with another relative) Timeline can be used.

Can you tell me how old you were when the first separation occurred?

What was the nature of that separation?

How long did that last?

Any positive things that you remember about that separation?

Any negative things that you remember about that separation?

Can you tell me about the contact, if any, that you had with your mother/father during that separation?

Was that different in any way to the hospital admission separation(s)? If yes, how was it different?

Ask, if relevant, how any reunification was experienced by the participant. For example, ‘can you tell me about how it was for you when your mother/father was released from prison?’

If there are additional other separations, then ask the same questions for each if this is likely to elicit rich information. E.g. if there was a prison separation and then the parents divorced these should each be explored in depth. If there are several short prison sentences, an overall question about whether there were differences in their experience with each may suffice. Aim to guide the participant through these in chronological order (again the timeline can be used if helpful).

Again, simple prompts will be used to enable the participant to say as much as they wish to.

## Family and Relationships

It would be really helpful if you could tell me more about your relationship with your mother/father [who was admitted to the secure hospital]?

Apart from your mother/father [the parent who was in hospital] can I ask about your relationship, if you have one, with your mother/father (who isn't the parent discussed so far)? Again, prompts will be used and appropriate follow up questions used to find out whether they have been in a parental role to the participant and the quality of that experience. In particular, if not evident from the initial response 'would you say that it was a warm, loving relationship?'

Has anyone else been like a parent to you? If participant is unsure, clarify with 'sometimes an aunt/uncle/neighbour may take on a parental role. Or people sometimes find that they have a particularly supporting relationship with a friend's parent or an understanding teacher or sports coach'. Again brief additional questions will seek to find out about the quality of that experience for the participant and the relationship between this person taking on a parental role and their mother/father being in a secure hospital.

And can I ask, who are the important people in your life to you now?

How often do you see them?

And what's that time like?

And would you feel confident that they would step up and help you if you needed it?

- Would they help with practical things like somewhere to stay, or if you needed to borrow some money?

Can you talk to them?

Do they understand you?

Some people have very strong bonds with animals, like pets, for example? Do you have any pets or other animals that are important to you?

I also wondered, from your perspective, how you feel your mother/father's admission(s) impacted on the rest of your family?

And from your perspective, do you feel that your experiences of your mother/father's difficulties have affected your own identity or sense of who you are?

- If yes, 'can I ask, how?' Prompts will be offered as appropriate, to help the participant expand on this.

## Life now

I'd like to ask a little [more] about how things are for you now.

You told me that you live alone/with x. How long have you been living with x/on your own? If they give a short time frame (e.g. <1 year) ask what were your living arrangements before then? Do you feel safe in your current home? Is it somewhere you feel comfortable and can relax?

May I ask, do you have any religious or spiritual beliefs?

- If no, have you ever had any?
- If yes, 'can you tell me about those?' And, 'how important are these to you?'

You told me that you're working as x/not working currently.

- Could I ask how things are for you financially?

- Add a prompt if necessary to deduce whether they have any financial worries?
  - o E.g. Can you afford to treat yourself sometimes?

Are there any professionals supporting you or involved in your life currently? E.g. social worker, CPN, third sector.

Generally, do you feel that you're able to overcome challenges in life?

What things do you do, or what strategies do you use, to cope with challenges?

Currently do you care for anyone or have any people who are dependent on you?

If yes, 'who?' 'What's that like?'

If not already evident, 'have you ever been in a caring role for a parent or other adult?'

If yes, 'can you tell me more about that?'

If no, probe a little more e.g. 'were there ways in which you helped your mother/father/parents at home?'

### Health and well being

If I could ask a few questions about health and wellbeing for you and your family?

How is your physical health currently?

Have you had any previous physical health problems?

Have you ever had to go to A&E or stay in hospital?

Do you find that you've often got aches and pains, like headaches, back ache or tummy ache?

Could I ask, do you do any exercise or participate in sport in an average week?

If yes, 'would you say that on average you participate in exercise that leaves you out of breath, at least once a week, for 30 minutes or more?'

If no, has there ever been a time in your life when the answer would have been yes? If so, when?

And in terms of your own mental health, do you have, or have you ever had, any difficulties?

- If they say **no**, then ask, 'do you take any medication to help keep you well? Are you prescribed any medication? Could I ask what for? If not covered, 'do you ever feel low in mood or find yourself feeling quite anxious?' If no, 'Have you ever had any difficulties like this?' 'Do you ever worry about having difficulties in the future?' If yes, 'can you tell me more about why you think that?'
- If they say **yes**, ask 'what sort of difficulties do you have? Do you take any medication to help with that? Have you ever needed to stay in hospital?' If yes, 'did you agree to be in hospital or were you detained under a section of the mental health act?'

Does anyone [else] in your family have any mental health difficulties?

If yes, could you tell me more about that? Do you know if they have a diagnosis – if yes what? Are they on medication to help with that? Have they ever needed to be in hospital?

Do their difficulties limit their life would you say?

If not already covered, 'may I ask, do you drink alcohol at all?'

- How many days, if any, have you had a drink in the last week?

- If yes, have you ever had any difficulties in relation to your drinking?

Have you ever used any drugs or substances that weren't prescribed by a healthcare professional?

- If yes, 'could I ask what that was?'
- How many days, if any, have you used that in the last week?
- Have you ever had any difficulties in relation to this?

Has anyone [else] in your family ever had difficulties with alcohol or other substances? Could I ask as well, whether you have been in any trouble with the law at all? If yes (and the participant seems sufficiently comfortable talking about this), ask 'has that happened often?' 'What sort of things have got you in trouble?' 'Have you ever been in prison?' Has anyone [else] in your family [apart from your mother/father if relevant] been in trouble with the law?

### Education and peer support

If I could ask about school, you told me you left school aged x, can I ask how school was for you? Offer prompts. I have a visual scale which you're very welcome to use to indicate how school was for you at different ages if that's helpful? You're welcome to use as many of these scales as you like and you can use them to show your experience at different ages, or different schools, whatever captures your experience best.

During your time at school, did you take part in any extra-curricular activities or after school clubs?

- expand with brief follow up questions

Would you say that you got into much trouble at school?

- If yes, 'did that ever result in you being in detention? Or suspended? Or excluded?'

At school, did you need any additional support?

If yes, ask 'did you receive that support?'

Could you tell me about your relationships with the other children at school?

Add, if necessary, 'can I ask how things were for you at school in terms of friends and friendship groups?'

If not already evident, 'were you bullied in any way at school?'

If yes, 'if you're comfortable to do so, could you tell me more about your experience of that?'

Did you have anyone who you could really confide in, who you felt understood you?

Can you tell me a little more about that?

### Closing remarks for this section

Thinking over everything we've talked about so far, is there anything you would like to add about any aspect of your experience?

Could I ask you to say in summary then, how you feel that your mother/father's admission(s) to a secure hospital has/have impacted on you personally? And on your relationship with you mother/father?

Can I ask you to say a little more about how? Add prompts if necessary.

### Questions about the research process

I wonder if I could finally ask a few questions about your thoughts on the research?

Was there any area of your life or experience that we haven't asked about that you feel would be important to capture?

Were there any questions that made you feel uncomfortable or could have been worded better?

At this time the research team are interviewing only adults, but we would be interested to know whether you feel you would have felt able to take part in the interview when you were younger?

If yes, at what age (ascertain what the youngest age the participant thinks it would have been okay at)?

Do you think you would have said anything different at a younger age?

Would there be anything that we would need to do differently if we were to ask to speak to children at a younger age?

What were your thoughts on the visual and diagrammatic options (this might be re phrased if the participant hadn't utilised any)? Do you think you would have found these more/less useful at a younger age?

Does the participant have any other comments about the interview process?

Does the participant have any other comments about the research team's thoughts to interview younger children?

### ***Closing section***

Interviewer thanks the participant for their time.

Interviewer advises the participant that if they have any burning thoughts that they want to add after they have left the interview, then they can contact the research team on email, by phone or by writing to us. If the participant expresses a preference for contacting the same person who has interviewed them then this can be arranged by, for example by putting in the subject heading on an email FAO interviewer's name, or by texting the mobile number asking for a phone call from x.

Interviewer reminds participant that they can reimburse their travel if they came by standard class on public transport or drove? If the participant does not have receipts on them the researcher can offer the participant a SAE to send receipts in and we would then send them a cheque (they would need to include an address to send the cheque to and instructions on who to make the cheque payable to). If not already noted, the interviewer will ascertain whether the participant would like to receive a copy of the final report and if so, how to get this to them.

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\* We have used mother/father throughout the interview schedule, but interviewers would use the language of the participant – so if they say 'birth mum', this would be the language used unless they used a very individualised name for their parent figure and the interviewer felt it might be odd to use that name, in which case they would ask after this transition question, how the participant would like the interviewer to refer to [whatever name the participant had used for their parental figure].

\*\*Similarly, we have used 'secure hospital' throughout, but if the participant called it forensic or some other term, then the interviewer would use that.

## Appendix F: Original project information sheets

### Participant Information Sheet (v0.3 16.03.2018)

<p><b>Will taking part be helpful to me?</b></p> <p>We don't think that taking part will help you as an individual. We hope that the research may lead to improvements for people with similar experiences in the future.</p> <p><b>Are there any disadvantages to me?</b></p> <p>Talking about your experience may be upsetting. If you are upset, the researcher will ask if you need a break, or even to bring the interview to a close. We would ask you to stay with the researcher until you feel better and if you want us to contact anyone to help, we will.</p> <p>Unfortunately we cannot pay you, but we can give you the money back for standard class rail or bus tickets, or for petrol if you drive (45p per mile), to cover your travel from home to the interview and back. For train or bus travel you will need to give us your receipt.</p> <p><b>Confidentiality</b></p> <p>Everything you tell us will remain confidential to the research team. This is true unless you tell us that either you or someone else could be at risk of serious harm. Then we would have to tell someone outside the research team, to keep that person safe. If this happened, we would discuss with you who we would speak to and what we would tell them.</p> <p><b>Who is organising and funding this study?</b></p> <p>Cardiff University and Abertawe Bro Morgannwg University Health Board.</p> <p><b>Who has reviewed the study?</b></p> <p>An NHS Research Ethics Committee, which has approved it.</p>	<p><b>What happens if I am interested?</b></p> <p>Someone from the research team would be happy to meet with you on a one to one basis, or speak to you on the phone. This can take as much or as little time as you need. Please feel free to talk to others about the study if you wish.</p> <p>Your choice about whether to take part will not affect your parent's care. You can change your mind at any time - even if you have signed the consent form. However, if you have already completed part of the interview, we would like to include your contribution in the research, unless you ask us not to do so.</p> <p><b>How to contact us</b></p> <p>If you want to take part or have any questions about the research please contact:</p> <p>Dr Natasha Kalebic Tel: 02920 688351 (Mon – Fri). Text: 07938 562257 Email: <a href="mailto:cpsh@cardiff.ac.uk">cpsh@cardiff.ac.uk</a></p> <p>Being the <b>child</b> of a <b>patient</b> detained in a <b>secure</b> <b>hospital</b></p> <p>We hope you will be happy with your interactions with the research team, but if you do wish to raise a complaint about any aspect of the study, please contact Prof. van den Bree, who is Independent to the research team.</p> <p>Email: <a href="mailto:vandenbree@cardiff.ac.uk">vandenbree@cardiff.ac.uk</a> Phone: +44 29206 88433</p> <p><b>Thank you for reading this information sheet</b></p>	<p><b>Exploring the experience of having a parent who is a patient in a secure hospital</b></p> <p><b>Participant Information Sheet</b></p> <p><b>Information about our research</b></p> <p>We'd like to invite you to take part in our research. Our aim is to find out about the experience and needs of adult children who have a parent who is, or who has been, a patient in a secure forensic hospital.</p> <p>This leaflet explains a bit about the study and what it would involve. Joining the study is completely your choice. If after reading this leaflet you have any questions please do get in touch with us – contact options are on the back.</p> <p>Prof Pamela Taylor, Dr Sarah Argent, Dr Natasha Kalebic and Dr Fran Rice. Department of Psychological Medicine and Clinical Neurosciences, Cardiff University.</p> <p>Dr Janet Parrott, Bracton Centre, OXLEAS NHS Foundation Trust.</p> <p>Prof Doug MacInnes, Canterbury Christ Church University.</p> <p>Dr Sandeep Mathews, Betsi Cadwaladr University LHB</p> <p>  </p> <p>  </p> <p>Participant information sheet v0.3 (16.03.2018) IRAS no 232035</p>
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<p><b>What are we doing and why?</b></p> <p>Maintaining positive relationships with family and friends is really important. One key relationship is that of parent and child. We know that up to half of all patients who are in secure hospitals have at least one child, but we know very little about the children's experience and needs.</p> <p><b>Who are we asking to take part?</b></p> <p>Anyone aged 18 or over, with a parent (or stepparent or any adult who has cared for you like a parent) who is, or who has been, a patient in a secure forensic hospital. We are inviting people who are currently aged 18+ but it does not matter if you were under 18 years when your parent was admitted to hospital. You need to be fluent enough in English to understand what is being asked of you and to tell us about your experience.</p> <p><b>What will happen if I choose to take part?</b></p> <p>You will meet once with a researcher who will interview you.</p> <p>Before the interview, the researcher will check with you that you understand the process and make sure that you are happy with all aspects of taking part. If you are, they will go through a Consent Form with you and ask you to sign this. This is written confirmation that you are happy to take part. You can still change your mind even after you have signed. Please keep a copy of the Consent Form and this Information Sheet if you wish.</p>	<p><b>During the interview</b></p> <p>The interview will take place at the one of the following places which best suits you:</p> <ul style="list-style-type: none"> <li>• Hadyn Ellis Building, Cardiff</li> <li>• Caswell Clinic, Bridgend</li> <li>• Ty Llewelyn, Llanfairfechan</li> <li>• Bracton Centre, Dartford</li> <li>• Other clinical sites if preferred, although a site outside of ABMUHB/BCUHB/OXLEAS NHS FT would require the agreement of the site's service provider.</li> </ul> <p>Interviews can be as short or as long as you wish, but we hope you will feel comfortable talking to us for up to an hour. Some interviews may last longer. The important thing is for us to hear everything that you want to tell us. You can ask for a break, or for the interview to stop at any time. We would like to audio record the interview, but if you don't like that idea, you can just talk to the researcher, who will make notes during the interview.</p> <p><b>What will I be asked about?</b></p> <p>The researcher will first ask for some basic information, such as your age and occupation. Then the researcher will ask you about your experience of having a parent who has been a patient in a secure hospital. There is no right or wrong response. It is important to us that we hear <u>your</u> story.</p> <p>The researcher will then ask some further questions to get a complete picture of your experience. Topics will include your own health (including any substance and alcohol use), how things are for you financially, whether you have ever had any trouble with the law, and what, if any, spiritual or religious beliefs you hold. Please remember though, that you may skip any of these questions if there are particular ones which make you uncomfortable.</p>	<p><b>What will happen afterwards?</b></p> <p>All information collected during the research will be kept in locked cabinets in Cardiff University. Any electronic notes and transcripts of the audio files will be password protected and anonymised, again within a university system. We will keep the data for up to 15 years after the study has finished, then it will be securely destroyed.</p> <p>Findings will be shared with the participating centres listed, then prepared for publication in professional journals. No one's personal details, or any information which could identify them, will be included in any shared information.</p> <p>If you would like to receive a report of the findings, please tell us and tell us the best way of getting this to you.</p> <p><b>When will the research end?</b></p> <p>We think that we will have been able to interview enough people (probably between 10 and 20 people) by around Autumn 2019 and as we will be analysing the content of the interviews as we go along, we should be able to present our initial findings by Spring 2020.</p>
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<p><b>What are we doing and why?</b></p> <p>Maintaining positive relationships with family and friends is really important. One key relationship is that of parent and child. We know that up to half of all patients who are in secure hospitals have at least one child, but we know very little about the children's experience and needs, and how services could better support them.</p> <p><b>Who are we asking to participate?</b></p> <p>Anyone aged 18 or over, with a parent (or stepparent or any adult who has previously had parental responsibility or cared for them like a parent) who is, or who has been, a patient in a secure forensic hospital. Participants need to be fluent enough in English to understand what is being asked of them and to tell us about their experience.</p> <p><b>What is asked of participants?</b></p> <p>Participants will meet just once with a researcher who will interview them, unless they would prefer also to meet prior to this, to discuss any aspect of the research before deciding whether to be involved or not.</p> <p>Before the interview, the researcher will check that the participant understands and is happy with all aspects of his/her participation in the research. If so, then the researcher will ask him/her to sign a consent form, and offer a copy of this and the Participant Information Sheet to keep.</p>	<p><b>What would being involved ask of me?</b></p> <p>We are inviting you to think about whether you know of any potential participants. If so, please consider making them aware of the opportunity to participate in the research. If the 'child' is interested in knowing more, then please either give them a 'Participant Information Sheet' or, with their consent, forward their contact details and preferences to Natasha Kalebic (see back page) and we will contact him/her. Please do make the 'child' aware that whether or not s/he participates in the research, this will have no bearing on your involvement with them or on their parent's clinical care.</p> <p>If you are aware of a patient having a child aged 18 years or over, but do not have an existing professional relationship with the 'child', then should you consider it clinically appropriate, we ask you to make the parent-patient aware of the opportunity for their 'child', perhaps by passing on this leaflet, which s/he, in turn, could pass on to the child and/or ask the child to contact us directly if the child wished to do so.</p> <p>Participant information sheets and posters will also be displayed in the clinical sites.</p> <p><b>How to contact us</b></p> <p>If you have any questions or comments about the research, please contact:</p> <p>Dr Natasha Kalebic Tel: 02920 688351 (Mon – Fri). Email: <a href="mailto:cpsh@cardiff.ac.uk">cpsh@cardiff.ac.uk</a></p> <p>Being the <b>child</b> of a <b>p</b>atient detained in a <b>secure</b> <b>h</b>ospital</p>	<div>    </div> <p><b>Exploring the experience of having a parent who is a patient in a secure hospital</b></p> <p><b>Health Care Professionals' Information Sheet</b></p> <p><b>Information about our research</b></p> <p>Please help us raise awareness among potential participants about our research. Our aim is to find out about the experience and needs of adults whose parent is, or has been, a patient in a secure forensic hospital.</p> <p>This leaflet explains a bit about the study, what it would involve for participants, and how we would like staff to be involved. If after reading this leaflet you have any questions please do not hesitate to get in touch – contact options are on the back.</p> <p>Prof Pamela Taylor, Dr Sarah Argent, Dr Natasha Kalebic, Dr Fran Rice. Department of Psychological Medicine and Clinical Neurosciences, Cardiff University.</p> <p>Dr Janet Parrott, Bracton Centre, OXLEAS NHS Foundation Trust.</p> <p>Prof Doug MacInnes, Canterbury Christ Church University.</p> <p>Dr Sandeep Mathews, Betsi Cadwaladr University LHB</p> <div>    </div> <p>Health Care Professionals' Information Sheet v.0.2 (04.01.2018) IRAS no 232035</p>
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<p><b>During the interview</b></p> <p>The interview will take place at one of the centres:</p> <ul style="list-style-type: none"> <li>• Hadyr Ellis Building, Cardiff</li> <li>• Caswell Clinic, Bridgend</li> <li>• Ty Llewelyn, Llanfairfechan</li> <li>• Bracton Centre, Dartford</li> <li>• Other clinical sites if preferred, although a site outside of ABMU LHB/BCU LHB/OXLEAS NHS FT would require the agreement of the site's service provider.</li> </ul> <p>Interviews can be as short or as long as participants wish, but we anticipate that they will be around 60 minutes. For us, the important thing is to hear everything that participants want to tell us. Participants don't have to answer questions and may stop the interview at any time. We would like to audio record the interview, but this is up to the participant. The researcher will make notes during the interview.</p> <p><b>What will participants be asked about?</b></p> <p>The researcher will first ask a few simple questions to build rapport – e.g. age and occupation.</p> <p>Then the participant will be invited to say anything they like about his/her experience of having a parent who is/was a patient in a secure hospital. Once participants have responded, uninterrupted but with prompts, the researcher will ask some specific questions to build a complete picture. Again, no questions are mandatory.</p>	<p><b>Confidentiality</b></p> <p>Everything participants tell us will remain confidential to the research team, unless we were made aware that someone could be at imminent risk of significant harm. Participants would be aware of this from the consent process. In that event, we would discuss with the participant exactly who could help, and thus who we would speak to and what we would disclose.</p> <p><b>Will taking part be beneficial to participants?</b></p> <p>We don't think that taking part will help participants personally although they may appreciate the opportunity to tell their story. We hope the research may lead to improvements for people in similar situations in the future.</p> <p><b>Are there any disadvantages to participants?</b></p> <p>Talking about their experience may be distressing to participants. Interviewers will be attuned to signs of this and will behave sensitively – for example asking if participants need a break, or bringing the interview to a close. The researcher will encourage participants to stay with them until they feel better. If the participant would like us to contact anyone to help them, we will.</p> <p>Unfortunately we cannot compensate for participant's time, but we can reimburse standard class rail/bus fares, or mileage, to cover travel from their home to the interview and back, on production of a valid receipt, if applicable.</p>	<p><b>Who is organising and funding this study?</b></p> <p>Cardiff University and Abertawe Bro Morgannwg University Health Board.</p> <p><b>Who has reviewed the study?</b></p> <p>An NHS Research Ethics Committee, which has approved it.</p> <p><b>What will happen afterwards?</b></p> <p>All information collected during the research will be kept in dedicated locked cabinets in Cardiff University. Any electronic notes and transcripts of the audio files will be password protected and anonymised, again within a university system. We will keep the anonymised data for 15 years after the study has finished, when it will be securely destroyed.</p> <p>Findings will be shared first at participating centres, then prepared for publication in professional journals. No one's personal details, or any information which could identify them, will be included in any shared information.</p> <p><b>When will the research end?</b></p> <p>The nature of the study means that we can analyse data as we go along. This process allows us to identify categories of relevant information. Our sample is complete when we find no new categories in an interview. We expect this to mean we need to interview 10-20 people. We can't be precise about when this will happen as we are dependent on individuals to want to join the research – but we expect to complete by Spring 2020.</p>
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## Appendix G: Consent Form (v0.3 16.03.2018)

	 <div><b>GIG CYMRU NHS WALES</b></div> <div>Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg University Health Board</div>	 <div><b>Oxleas</b> NHS Improving lives</div>
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### Exploring the experience of having a parent who is, or who has been, a patient in a secure hospital

#### Consent Form



**Participant identification number:** \_\_\_\_\_ Please initial box



1. I confirm that I have read the 'Participant Information Sheet' dated..... (version number.....) for the above study. I have been able to ask any questions that I would like to, and these have been answered to my satisfaction. ☐
2. I understand that taking part is completely my decision and voluntary. I know that I can decide not to be part of the study and that this will have no effect on my parent's care. ☐
3. I understand that if I have completed the interview, I can still change my mind about my anonymised contribution to the research being included in the final results, up to 14 days after the interview. I understand though that once 14 days have passed after the interview, my anonymised data will be included in the final results. ☐
4. I understand that the information collected about me may be used to support other research in the future and may be shared with other researchers, or published, but that any information shared would not include anything that would identify me. ☐
5. I agree to take part in the above study. ☐
6. Optional: I give consent to have the interview audio recorded. ☐
7. Optional: I give consent for the use of quotations saying exactly what I've said in publications, although these will never include anything which would identify that I have said them. ☐
8. Optional: I give consent for my name and contact details to be securely stored at Cardiff University for up to 5 years after the study finishes and to be contacted in this timeframe about new opportunities to take part in related research. ☐


_____ Name of participant	_____ Date	_____ Signature
_____ Name of person obtaining consent	_____ Date	_____ Signature

 <div><b>GIG CYMRU NHS WALES</b></div> <div>Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board</div>	Consent Form IRAS ID: 232035 Version 0.3 (16.03.2018)	 <div><b>Canterbury Christ Church University</b></div>
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Bwrdd Iechyd Prifysgol  
Abertawe Bro Morgannwg  
University Health Board



Improving lives

## Exploring the experience of having a parent who is a patient in a secure hospital

*Has one of your parents, or someone who has looked after you like a parent, been a patient in a secure forensic psychiatric hospital?*



*We want to learn more about the experience of people in this situation - what helps, what are the challenges, and what could professionals and services do better?*

*If you're over 18 years old and would be interested in taking part in a confidential research interview, please get in touch, or let a member of staff know that you would like to be contacted by a member of the research team.*

*If you're a parent, would your child be interested in taking part? Would you like the research team to talk to you about what this would involve?*

*If you're interested to know more, have feedback, or even think you may wish to take part, please contact Dr Natasha Kalebic on:*  
Tel: 02920 688351 (Mon – Fri).  
Text: 07938 562257  
Email: [cpsh@cardiff.ac.uk](mailto:cpsh@cardiff.ac.uk)

*Being the **c**hild of a **p**atient in a **s**ecure **h**ospital*



Bwrdd Iechyd Prifysgol  
Betsi Cadwaladr  
University Health Board

## Appendix I: Peer reviews

### Peer Review of Protocol v0.1 by H Putkonen



NATIONAL INSTITUTE  
FOR HEALTH AND WELFARE

Peer Review  
Being the child of a patient detained

1(2)

October 4<sup>th</sup>, 2017

#### **EXPLORING THE EXPERIENCE OF HAVING A PARENT WHO IS, OR WHO HAS BEEN, A PATIENT IN A SECURE HOSPITAL**

##### **Being the child of a patient detained in a secure hospital**

##### **Peer review of PROTOCOL VERSION 0.1 26/09/2017**

This study will provide valuable information. It is true we presently have too little information on the children of parents who are or have been treated in a secure hospital. The methodology seems appropriate and relevant ethical issues appear to have been considered.

##### **Aims, methods, procedure**

Since we know little about the issue, a grounded theory method works well. However, I suggest that the protocol will include some more information on the theoretical framework before it is sent to the ethics committee. Not everyone is familiar with these concepts and methods.

I find the research question/aim sufficiently clear. With such little information on the subject it is valuable to try and find a testable model of the experience. With the open ended question the participants will have a true opportunity to speak about the matter as they wish. I did not receive the "semi-structured interview", so I cannot offer review of that. However, I do find it useful to have questions available to ensure sufficient information, if the participant does not offer it after the open ended question. I'd say the methods, as described, are appropriate for the questions posed.

Nevertheless, I have a few details I'd like to comment on. They are in the order of appearance in the protocol.

- The protocol seems to make a binary gender assumption. What if a participant's gender is non-binary? How will the "gender appropriate" false name of a trans person be defined?
- The protocol lists the persons with access to the data on several occasions. To ensure clarity, I suggest that the exact persons are named on the first appearance and not just on page 14. On the same issue, I suggest that the initials on p. 8 are clarified.
- The protocol assumes that the participants live in the community (p. 9). This issue is not mentioned in the inclusion/exclusion criteria. What if a child is not living in the community, but in another secure facility or a similar situation? Will such a person be offered the chance to participate? If yes, how? If not, why not?
- The table Study Summary (p. v) shows that the planned study period is two years. In the actual text this is not described. E.g. on p. 10 it says "...until the study ends" with no estimation of this.

##### **Ethical issues, risk of harm, benefits**

The protocol seems to address the relevant ethical issues. I find the described assessment and management of risk sufficient. For obvious reasons, this research could not be done with any other, less vulnerable group. As the participants of the current protocol will be adults, there is no necessity for further protection. However, a study with under aged children would be more





October 4<sup>th</sup>, 2017

challenging and it is an intelligent plan to first study these matters with adults to find out whether or not a further study with minors will be ethically sound.

It is mentioned that an adult male offspring has been interviewed about his views on the proposed research. I congratulate the investigators on this. I also find it excellent that this person will be part of the steering group. However, I suggest his role is elaborated further. What did he think of the protocol? Were any changes made based on his suggestions? If so, which and if not, why not? This would strengthen the ethical grounds of the protocol.

In present day society it is obvious that all groups need to be heard. If we are to know about our patients, we need to know about their children, too. This information will be good for both the child and the parent. The results of this research will be useful in planning services to help the children cope and also to make sure they can be helped so as to not start or continue an intergenerational cycle. It is also true that most parents thrive better when their children thrive. We as a society need to help these people not only for the general good but also for general safety.





Forensic Psychiatry as a field needs more research on the personal experiences of people involved in its organizations to further develop. This protocol will provide a valuable addition to knowledge in the field.

Hanna Putkonen

Senior Medical Officer, National Institute for Health and Welfare  
Adjunct Professor, [REDACTED]



Peer Review of Protocol v0.1 by H Hales



I've read through the protocol and made two comments in the margins and a typo - attached I thought it was fine the two thoughts were -  
1 - it is a big ask to ask them to come to you - I suspect you will lose participants - can you not go to them?  
2 - in the ethics bit you have said that you don't anticipate it being upsetting - actually I think it may well be upsetting for many - so it would be good to have a place for them to sit afterwards and a process of support or follow up to check they are ok a week later

Of course - I'd be interested in the interviews with those under 18 - to see what they think but ethics will be more complicated  
or interviewing those over 18 who had a parent in secure when they were under 18 ...

H  
Dr Heidi Hales  
Consultant Adolescent Forensic Psychiatrist



Subject: Re: Peer Review Request for our Study Protocol

Dear Heidi,

Thank you so much for reading the protocol and giving feedback.

We are hoping that some of the adults who we might interview will have had childhood experience of their parent being admitted and so that they can both tell us retrospectively how that was for them, and give us advice about how we might best approach interviewing younger children. Our original hope had been to interview children under 18 years, but given the Ethics Committee issues, it seemed that starting with older participants and demonstrating that it is important and relevant to talk to younger children from the content of the interviews with the adult aged children, before then asking for a substantial amendment to interview younger children, would be the best way forward. I don't know what your view would be on that?

I had originally expressed amenability to going to participant's homes and utilising lone worker procedures - although two of us would attend, but Pamela was not keen on this. However, your recommendation brings this back to the table for discussion. What I will note, is that at Caswell, where parent and child are in contact (even with adult children) our social work and FCPNs are generally very involved in bringing the 'child' to hospital to facilitate contact and those I've spoken to so far would do this for the research too in order to offer support.

I hope to be able to discuss all your feedback with Pamela tomorrow.

Regards,

Sarah



## Re: Peer Review Request for our Study Protocol



Mon 02/10/2017 16:03



that all sounds reasonable -

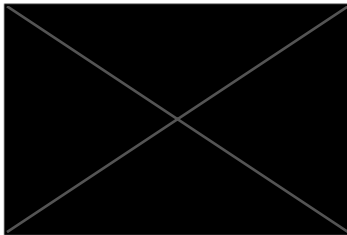
1 - to interview adult 'children' to find out what was important to them and what is distressing - to formulate how to manage an interview with someone under 18

2 - to meet with people at the unit when they are visiting

H

**Dr Heidi Hales**

**Consultant Adolescent Forensic Psychiatrist**



## **Appendix J: Protocol v0.1 (26.09.2017)**



## **EXPLORING THE EXPERIENCE OF HAVING A PARENT WHO IS, OR WHO HAS BEEN, A PATIENT IN A SECURE HOSPITAL**

**Being the child of a patient detained in a secure hospital**

**PROTOCOL VERSION 0.1 26/09/2017**

**IRAS Number:232035**

**SPONSORS Number: Awaited**

**FUNDERS Number: NA**

This protocol has been developed in line with NHS (Health Research Authority) Qualitative Protocol development tool (<http://www.hra.nhs.uk/hra-training/tools>). This protocol has regard for the HRA guidance and order of content.

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

**For and on behalf of the Study Sponsor:**

Signature:

Date:

.....

...../...../.....

Name (please print):

.....

Position:

.....

**Chief Investigator:**

Signature:

Date:

.....

...../...../.....

Name: (please print):

.....

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## KEY STUDY CONTACTS

Chief Investigator	Sarah Argent [REDACTED] and Pamela Taylo [REDACTED] [REDACTED]
Study Co-ordinator	Natasha Kalebic
Sponsor	Cardiff University
Joint-sponsor(s)/co-sponsor(s)	We await advice from Cardiff University as to whether they would want the NHS R&Ds involved to act as co-sponsors
Funder(s)	N/A
Key Protocol Contributors	Sarah Argent: [REDACTED] Pamela Taylor: [REDACTED] [REDACTED] Natasha Kalebic [REDACTED] [REDACTED]
Committees	Not established as yet.

## STUDY SUMMARY

Study Title	Exploring the experience of having a parent who is, or who has been, a patient in a secure hospital
Internal ref. no. (or short title)	Being the child of a patient detained in a secure hospital
Study Design	Grounded theory (qualitative) study
Study Participants	Adult offspring of people who are, or who have been, patients in a secure hospital
Planned Size of Sample (if applicable)	N/A – sample size in grounded theory is determined by the point at which no new categories of information are being discovered in new interviews. It is expected that 10-20 interviews will be needed to achieve this.
Follow up duration (if applicable)	N/A
Planned Study Period	Approximately 2 years
Research Question/Aim(s)	How do the adult offspring of patients in secure hospitals experience this aspect of their lives and how does this situation affect their lives?

## FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON FINANCIALSUPPORT GIVEN
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(Names and contact details of ALL organisations providing funding and/or support in kind for this study)	
ABMU Local Health Board	Funds [REDACTED] Cardiff university post

## **ROLE OF STUDY SPONSOR AND FUNDER**

The sponsor of the study is Cardiff University. The only funding is in terms of ABMU LHB providing the funding for [REDACTED] for her employment with Cardiff University. Other members of the research team are funded in terms of their salary by the organisation to which they are affiliated. At this time there is no additional funding for the project. ABMU LHB has not been involved in the design of the protocol, but as one of the proposed NHS sites is part of ABMU LHB, the local R&D department will be involved in reviewing the protocol and determining its acceptability to that proposed site.

## **ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITTEES/GROUPS & INDIVIDUALS**

### **Study Steering Group**

Although it is not yet formed, we plan to have a study steering group, which would include a clinical member of staff from each organisation (the NHS LHB (Wales) or the NHS Trust (England)) through which we are recruiting participants. This clinical member would be a different person to the PI at that site. We are also fortunate to have an adult child whose mother has been a patient in a secure hospital, who has already provided input in terms of the research acceptability and design, and who has said he would be keen to participate on any steering group. We very much hope that he will continue to be in a position to contribute in this way when the research commences.

## **PROTOCOL CONTRIBUTORS**

The protocol has been compiled by the research team and the sponsor has not been involved in this process, although the sponsor will have to approve the protocol, in order to provide sponsorship. The design, conduct, data analysis and interpretation, manuscript writing, and dissemination of the results of the study will be the work of the research team.

The only funding is in terms of ABMU LHB providing the funding for [REDACTED] salary, for her employment with Cardiff University. ABMU LHB have not been involved in the development of the protocol but as one of the clinical sites is part of ABMU LHB, the local R&D department will be involved in reviewing the protocol and determining its acceptability to that proposed site.

The study has been discussed in broad terms with a man, whose mother has been a patient in a secure hospital. He has not directly contributed to the protocol itself but his feedback about the acceptability of the research and of the proposed design of the research has been integral to its development.

### **KEY WORDS:**

Parent-child relationship, Forensic Psychiatry, Secure hospital , Lived experience



## STUDY FLOW CHART

A potential participant becomes aware of the study and either contacts the research team or requests that the research team contacts them.



Initial contact and information giving.



Minimum of 24-hour period for potential participant to consider whether they want to be involved or not



Meeting with the researcher to obtain informed consent and to conduct the interview.



There is scope for a second meeting to complete the interview if unforeseen circumstances preclude it being completed in one session, but this will be the exception rather than the rule.



Involvement in the study ends at the end of the interview. If participants have indicated that they would like a copy of the final report this will be sent to them.



# Exploring the experience of having a parent who is, or who has been, a patient in a secure hospital

## 1 BACKGROUND

The aim of the study is to understand the core concern of the children of patients who are detained, or who have been detained, in secure psychiatric settings. The research will seek to discover a testable model of their experiences and understand what factors constitute a barrier to healthy survival and what factors facilitate such an outcome.

Children, as described by UNICEF (1990), are dependent on “adults for the nurture and guidance that they need to grow towards independence. Such nurture is ideally found in adults in children's families but when primary caregivers cannot meet children's needs, it is up to society to fill the gap” (UNICEF, 1990).

Primary caregivers' ability and, indeed, inclination to provide such nurture may be compromised by a range of difficulties. Parents who become patients detained in forensic psychiatric settings have a complex mix of problems which may interfere with their capacity to parent. These include severe and chronic mental disorder, which will often have predated the parent's admission to hospital, separation from the child – perhaps as a result of the admission, perhaps also preceding it - and commission of serious violence, often in the form of a serious violent offence relevant to the admission. Further, the violence is often towards a family member. From a staff perspective, the extent to which admission to the unit means full separation from the child, at least for a period, depends on two main things – concern about the immediate physical and emotional safety of any child and, in the case of pre-trial patients, legal restrictions on contact because the child may be a material witness.

The commonest age range for admission to a secure hospital unit is 25-35, so many of the children involved are under 18 years and thus dependent on adults. Some patients, however, have children of adult age. As adults, they are likely to have a different set of needs from younger children, which we are keen to identify also, but they are also likely to have recollections of experiences of situations at a younger age relating to the current or previous parental admissions. They should be able to give us invaluable insights into the needs of younger children from their own recollections and also offer us guidance as to whether and how we could appropriately seek to learn about the experiences of younger children directly from the children themselves at the time of their parent's hospitalisation.

## 2 RATIONALE

There is little literature to date on even the numbers of children likely to be affected by a current or previous admission of one of their parents to a secure psychiatric setting. The few relevant published papers mostly focus on the number of parents rather than the number of children. There are just three publications, all UK based, which consider parenting as a facet of the lives of secure hospital patients (Chao and Kuti 2009; Gow et al. 2010 and Parrott et al 2015). Gow et al. (2010) simply mention the prevalence of parenthood as part of the demographic information, in a survey looking more broadly at the characteristics of inpatients, although it is encouraging that they included their parental status as part of this.

In terms of child-parent contact after the parent's admission, Chao and Kuti (2009) looked only at children aged under 18 years and found that just a third had any contact with the detained parent. Parrott et al. (2015) included children of any age and found that two-thirds were in contact. Parrott et al. (2015) also conducted narrative interviews with 18

parent-patients, which highlighted the importance to patients of their role as parents. They did not however explore the views or experiences of the children.

Our work (Argent et al. 2017), also looked at the parent-child contact before and after admission as well as the impact of the parental admission on any parental responsibility held by the parent before and after their admission. What was striking in these findings was that parent-child contact after admission, even, and indeed especially, among those parent-child pairs who had been living together prior to the parental admission, was most likely to continue after admission if the child was aged 18 or older and thus had freedom of choice as to whether to continue that contact or not.

In the absence of a body of literature which encapsulates the child's voice in this situation or indeed any objective measures of outcome, it seems appropriate to scrutinise the literature for any evidence around the facets of these children's experiences. First, there is the fact that the parent must have a mental disorder if they are detained in a psychiatric setting. There is literature which focusses on being a child whose parent has a mental disorder. Additionally, to warrant the security of these hospital placements, the parent must pose a risk to others, and this will often be evidenced through a severely violent index offence, which under other circumstances would attract a custodial sentence. Again, there is literature on the experience of having a parent who is incarcerated in prison. The other facet of these children's experience is the separation from their parent. While there are many reasons for this, each perhaps adding an extra burden on the child, considering the effects on children of a parent being deployed in the military or the child having been evacuated away from the parent during the second world war seem likely to provide best comparison material which reflects on neither offending nor mental disorder. What is notable though even after systematically searching these various bodies of literature, is that there is little which captures the voice and the experience of the child themselves. Any child whose parent is detained in a secure psychiatric hospital is likely to face a range of problems, including having at least one parent with a severe and enduring mental illness, having committed a seriously violent index offence and separation or limited and scrutinised contact with them for an undefined period. It seems imperative that we take steps to hear from these children directly about how they experience all this and what they consider their own needs to be.

### **3 THEORETICAL FRAMEWORK**

Given the absence of any research which considers the experience of children who have a parent who is, or who has been, detained in a secure psychiatric setting we propose a qualitative approach as the study is necessarily exploratory in nature. We propose using a grounded theory method to inform both the interview process and the analysis of interview transcripts. This will enable participants to tell their story as they wish, uninfluenced by any researcher preconceptions or bias. The following semi-structured part of the interview will ensure that a range of aspects of the participants' lives is also covered systematically. Analysis of the narrative data depends on, first, line by line coding of data categories, followed by a process called constant comparative analysis of these categories so that higher order categories may be found in the data and the core concern and model of experience be allowed to emerge from what the participants have said.

### **4 RESEARCH QUESTION/AIM(S)**

We want to understand the experience of people who have a parent who is, or who has been, a patient in a secure psychiatric hospital. Experience here is meant very broadly and

with the semi structured questions we have tried to cover a range of facets of life and functioning.

#### **4.1 Objectives**

To find a testable model of the experience of having a parent with a serious and chronic mental disorder who is regarded as posing sufficient risk of harm to others to have been detained in a secure hospital.

#### **4.2 Outcome**

A model which encapsulates and conveys the core concern of people who have a parent who is, or who has been, a patient in a secure psychiatric hospital, their vision of its resolution and of those characteristics within themselves and the therapeutic or wider environment which have helped them to resolve their concerns and those which have been a barrier to resolution.

### **5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS**

The study follows a grounded theory approach, with open interviewing of adult children (18 years or older) who have, or who have had, a parent detained in a secure hospital.

#### *The interview*

The interviews would be conducted by an appropriately trained member of the research team.

The interview will open with a reminder that our primary interest is in the participant's thoughts, feelings, actions and needs in relation to having a parent in the secure hospital. They will be reminded that the interviewer has no role in the treatment and care of the parent and that we are not in a position to give any information at all about the parent or to confirm or deny any beliefs that the child may have about the parent. We will assure the interviewee of confidentiality to the research of all information given unless that information suggests that there is an imminent risk of harm to the participant or to the patient. In the latter event, the participant will be engaged in discussion about who should be informed of the risk, but the fall-back position would be that the responsible clinician of the participant's parent would be given the information, restricted to just that information which suggests risk of harm.

The interview will commence with a few basic questions about the participant, such as their age, educational achievement, current occupation and living arrangements. Such questions, requiring simple answers, have the double purpose of yielding relevant contextual information and ice breaking before the open ended question about the participant's experience of being a child whose parent is or has been a patient in a secure psychiatric setting.

*'Please tell me something about how it has been to have your mother/father as a patient in Caswell/Bracton/Ty LLwelyn.'*

This creates an opportunity for the participant to say as much as they wish to, with limited prompting from the interviewer, without introducing interviewer biases.

Once the participant has absolutely nothing to add, the more structured systematic questions (as on the enclosed 'semi-structured interview') will be asked. Although these questions may remind participants of difficult subject matter or memories, participants will be reminded that they don't have to answer any question that with which they don't feel comfortable and that they can ask for a break at any time. The opening question in any area is deliberately broad to offer participants the option of touching loosely on it, or in more depth. Whilst follow up prompts from the interviewer will seek more in depth

information, interviewers will be trained to be attuned to signs of distress or discomfort from the interviewee and will behave sensitively. Furthermore, the structured questions will only be asked if the participant has not covered the material already. If the participant appears to be struggling at any point, then they will be offered a break or for the interview to come to a close. The researcher will remain available to the participant to assist in any way required with support or practical arrangements until the participant leaves the building. In the unlikely event that the participant becomes distressed to the point of wanting some assistance to get home or a friend or relative to attend, the researcher will help to facilitate that.

#### *Data handling, protection and anonymisation*

Data generated by the study will include:

- Consent forms
- An excel document linking the participants' names and the allocated anonymised code and, if applicable, the gender appropriate false name given to them.
- Audio files of the interviews (where participants have specifically given their consent for this)
- Notes made by the interviewer during the interview
- Transcription of the interview

All members of the research team will comply with the requirements of the Data Protection Act 1998 on collection, storage, processing and disclosure of personal information.

#### *Anonymisation*

When a participant gives their consent to be interviewed they will be allocated an anonymised code, which will appear on their consent form. For ease of reading, in any subsequent report for publication the participant will be given a false but gender appropriate name for that purpose alone.

Only the code will be on any other documentation.

If the participant agrees for the interview to be recorded, then we will prepare a card for the participant to read out, stating their research number, but not name for the tape, and their agreement to being audio recorded. We will ask each participant to refer to other on the tape by their given name only or according to their relationship with the participant, in order to avoid having any data on the recording which would make any other party identifiable.

The only documentation, which will include both the participant's real name and the related code, will be the consent form and an associated excel document. The consent forms will be filed in a locked cabinet at Cardiff University which is separate from the locked store of all the other paper data. The electronic record (the excel document) will be kept separately from the main database and will be password protected, on a university computer, to which only members of the research team will have access.

#### *Transportation of materials between sites*

All anonymised data generated at the clinical sites will be transported to Hadyn Ellis Building, Cardiff University, where it will then be securely stored in a locked filing cabinet when not in use by a member of the research team.

Consent forms, which include participant names, will be securely mailed to the university from the site so that personal identification data is never linked with the narrative data during transit.

If the research team are conducting interviews over several days at a participating site away from Cardiff, then the data generated will be kept at the participating site, locked in a draw or filing cabinet, until the research team member(s) can transport it to Hadyn Ellis Building.

#### *Audio tapes and transcription*

Any audio tapes with interview(s) on, anonymised in the way described above, will similarly be transported from the interview site to Hadyn Ellis Building by a researcher and will be kept in a locked filing cabinet in Hadyn Ellis Building apart from when they are being transcribed. As with other study data, they will be kept in this secure location for up to five years.

The transcription of the taped interview will be conducted by a member of the research team and will be completed at Hadyn Ellis Building. The transcription will be onto a word document, which will be saved under the anonymised code allocated to the participant.

The document will be password protected and only members of the research team will have access. Print outs of the transcribed interviews will be necessary for the process of analysing them, but will be locked away when not being used.

Any quotations from the participants, which are included as supporting data in any paper submitted for publication, or included in oral or poster presentations, will be such that the participant's or participant's parent's identity would still be protected. They would be attributed to the false but gender appropriate name given, and any potentially personally identifying information, such as details of the offence, would be removed.

#### *Interviewer's notes*

During the interview, the interviewer will make notes. The paper on which the notes are made will only have the participant's anonymised code on them. The notes will be transported to Hadyn Ellis Building by the interviewer and securely stored as with all the other data, for up to five years, then securely destroyed.

#### *Access to the final study dataset*

The final, fully anonymised dataset will be accessed by the two chief investigators and the research co-ordinator (Pamela Taylor, Sarah Argent and Natasha Kalebic), the named co-investigators and *bona fide* assistants, approved by the Chief Investigator, who sign an agreement to comply with all relevant aspects of this protocol.

## 6 STUDY SETTING

This is a multi-centre study with four proposed sites, three of which are NHS sites and one of which is a university site. The NHS sites are necessary to identify and recruit potential participants.

The sites proposed as centres from which we would recruit such adult children, are the three NHS sites, which are:

- Caswell Clinic, Bridgend.
- Ty Llewelyn Unit, Llanfairfechan.
- Bracton Centre, Dartford, Kent.

All three clinical sites are medium secure forensic psychiatric hospitals.

Caswell Clinic has been chosen as a site as two members of the research team have

clinical roles there. Ty Llewelyn was considered an appropriate extension as there is a working relationship between the North and South Wales sites clinically, and also through the Offender Health Research Network – Cymru (OHRN-C). This will also bring an all Wales perspective to the work.

The Bracton Centre is proposed to ensure that the prospective pool of participants includes a more urban and ethnically diverse sample than that available in Wales, and because the co-investigator has already published in the field and worked closely with one of us previously.

All three of these NHS sites will be used to advertise the study, and to identify and recruit potential participants. The three NHS sites will also generally be used as the sites for speaking with (potential) participants, whether as part of the informing and obtaining consent process, or to conduct the interviews. Private rooms will be made available at each site for these purposes. For potential participants who might find it easier or preferable to travel there, we can also offer similar facilities at the Hadyn Ellis Building, Cardiff University, which has a small outpatient and research participant area within the building, but separate from the academic staff accommodation.

## **7 SAMPLE AND RECRUITMENT**

### **7.1 Eligibility Criteria**

Any child who is aged 18 or older at the time of recruitment and who has, or who has had, a parent or primary caregiver in a secure hospital would be eligible. ‘Primary caregiver’ could include, for example, stepparent, foster parent, adopted parent; this list is indicative and not exhaustive. The primary caregiver could have been detained in any level of security within the secure psychiatric estate i.e. low, medium or high security, although the initial plans for means of recruitment suggests that most parents will be under current detention in conditions of medium security. Participants would have to be sufficiently fluent in English for the researcher to be satisfied, from discussion in English, that they have capacity to provide free and informed consent and are able and willing to do so. The participant also has to be sufficiently fluent in English that they can participate in the interview. The consent procedure is covered in more detail below.

#### **7.1.1 Inclusion criteria**

- Have, or have had, a parent/primary caregiver in a secure hospital.
- Aged 18 or over.
- Sufficiently fluent in English.
- Has capacity to consent

#### **7.1.2 Exclusion criteria**

- Aged 17 or under
- Non-English speakers.
- Unable to give informed consent.

## **7.2 Sampling**

### **7.2.1 Size of sample**

It is anticipated that between 10 and 20 participants will be needed for this part of the



study, but the actual number is determined by ‘data saturation’, which is when no new categories of data are emerging in new interviews. On reaching this stage ‘data saturation’ is said to be complete and no further interviewees *are required*, however, there is an option for some preliminary testing of the emergent model. If there were more adult children who had expressed a wish to participate than we might strictly need for the core, qualitative study, we would continue interviewing on this basis, but not seek to expand the study to a new centre. We would not want anyone who had expressed a wish to be involved with the research to be precluded from having the opportunity to tell their story (provided they met the inclusion criteria).

Due to the qualitative nature of the proposed research, no statistical analyses are involved and no power calculation can be applied.

### **7.2.2 Sampling technique**

We propose to adopt a purposive sampling approach. In brief, we would readily accept any eligible volunteer as a participant for the first interview, and then try to recruit a rather similar person for the second interview. This enables some simple testing of the interview strategy, as, for example, some common ground in responses might be expected if the first two participants were women with a father recently admitted to the hospital after a serious assault within the family. Thereafter, every effort would be made to include participants who are as diverse in themselves and their experience as possible, as this provides both maximum richness of data and hastens data saturation.

## **7.3 Recruitment**

### **7.3.1 Sample identification**

We have already secured the agreement of prospective Principal investigators (PI) at Caswell (SA), Bracton (JP), and Ty Llewelyn (SM).

Recruitment would involve:

Through the local PI at each site, the research team from Cardiff would arrange and provide an initial presentation to the clinic staff and to patient groups, where appropriate, to explain the purpose of the research and the nature of the proposed study. Through this process and the provision of information leaflets and the display of posters, we would look to generate awareness through the clinic’s patients (inpatient and outpatient) and staff, encouraging patients or staff to identify prospective ‘child’ participants.

Staff, if they had an existing relationship with the ‘child’, would be invited to make the ‘child’ aware of the opportunity to participate in the research, and if the ‘child’ expressed an interest in knowing more, then, through the staff member, they could forward their contact details and preferences to the research team. It would be essential that if staff approached the ‘child’, that the child was fully aware that the research is separate to the direct clinical care team of their parent and would not affect any of the support or services offered to either them or their parent.

If staff are aware of a patient having an adult child, but do not have an existing relationship with the child, then they would be requested, if they felt it clinically appropriate, to make the parent-patient aware of the opportunity for their child, and if they considered it appropriate, they could then tell their child. If the ‘child’ was interested to know more, the parent-patient could pass the ‘child’s’ details to the research team who could then approach the child directly. Staff and patients will also have copies of the ‘Participant Information Sheet’, so they could provide this for the ‘child’, so that they can make contact with the research team directly if the ‘child’ prefers.

Participant information sheets and posters will also be displayed in the clinical sites, so if children visiting a parent in the clinic saw the information and wanted to know more they

could contact the research team directly or ask staff or their parent-patient to let staff know that they would like to be contacted by the research team.

If the parent-patient was aware of the opportunity for their child, through either the initial presentations by the research team, or by seeing posters or information leaflets in the clinic, and if they considered it appropriate, they could then tell their child. As above, if the 'child' was interested to know more, the parent-patient could pass the 'child's' details to the research team who could then approach the child directly. Patients will also have access to copies of the 'Participant Information Sheet', so could provide this for the 'child', so that they can make contact with the research team directly if they prefer.

### **7.3.2 Consent**

Once prospective participants had been recommended, they would be contacted by the researcher to arrange a convenient time and place, or means, to discuss the research. If the prospective participant had made the initial contact with the research team themselves, then arrangements would be made in the same manner. We would encourage questions and discussion, face to face or by phone. If provisionally consenting, then the prospective participant would be invited to meet at the university or hospital venue which would be easiest for them to access.

Prospective participants would be advised that their standard class travelling expenses or mileage at standard university rates would be refunded on presentation of receipts where applicable, but there is no payment for participation.

Full, written consent to participate would then be sought from still interested participants. The potential participant's capacity to consent freely would be estimated by the researcher, from the nature and quality of the interaction when going systematically together through the information sheet. It is not anticipated that any more stringent approach would be required as potential participants would almost certainly be free living in the community. The researcher would also check that the participant felt that s/he had had sufficient time to consider participation. The prospective participant would inevitably have had the information sheet and basic information for well over 24 hours before the session with the researcher as this will be ensured when scheduling the meeting. In view, therefore, of the likelihood that many if not most of these participants would have had a considerable journey to attend for this discussion, if the person wished to go ahead with the interview straight away after formally providing their written consent, then that would happen.

## **8 ETHICAL AND REGULATORY CONSIDERATIONS**

Ethical considerations around this study are almost entirely about safeguarding of the data. As we have so little information about potential participants, we cannot be sure that they will have no mental health problems of their own. We are aware that we need to be sensitive to this possibility, but we are not approaching them as patients, but rather as community living members of the public who happen to have a relative in secure hospital.

### *Benefits of the study*

It is unlikely that the research will be of direct personal benefit to participants, but it would allow the voice of these children to be heard collectively for the first time. This can only be achieved by talking directly with the children themselves. The research is also potentially beneficial in terms of broadening our understanding of whether it might be appropriate to seek the views of younger aged children to get a real time view on their experience.

### *Adverse consequences of the study*

We don't believe there are any, but acknowledge that as the interview will touch on potentially distressing issues, participants could feel upset at times during the interview. We have already noted that the interviewer will be trained not only to conduct the interview but also to contain any acute distress and manage safe closure.

### *Research Ethics Committee (REC) and other Regulatory review and reports*

Before the study commences a favourable opinion will be sought from an NHS REC for this study protocol.

If approved, the participant information leaflet, the consent form and the poster would be displayed at the clinical sites.

All correspondence with the REC will be retained.

An annual progress report will be submitted to the REC within 30 days of the anniversary date of the favourable opinion and annually thereafter until the study ends.

The Chief Investigator will produce annual reports as required and will notify the REC at the end of the study or if the study ends prematurely, together with an explanation as to why the study has ended early. Within one year of the study formally ending, the Chief Investigator will submit a final report to the REC, which will include the results and any publications/abstracts.

## **8.1 Assessment and management of risk**

There is the possibility that during the interview a participant will disclose information that demonstrates a significant risk to themselves or others, either from the participant or from someone else. We have prepared for this possibility by discussing how to manage such information with participants before the study starts, as part of the consent process.

It is impossible to give a one size fits all plan in terms of exactly how we would proceed, but disclosure of self-harm information would lead to negotiation with the participant as to who should be contacted, with a trusted relative or general practitioner as the most likely, and disclosure of some specific previously unreported risk from the patient-parent or to the patient-parent would be referred to the clinical team through the responsible clinician.

## **8.2 Research Ethics Committee (REC) and other Regulatory review & reports**

Before the start of the study, a favourable opinion will be sought from a REC. Researchers will comply with requested routine reporting and, in the event of adverse incidents, report those to the supporting NHS R&D departments according to the prescribed format.

### **This is NHS REC reviewed research and therefore the following apply:**

Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.

All correspondence with the REC will be retained.

The Chief Investigator will produce annual reports as required.

The Chief Investigator will notify the REC of the end of the study.

An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.

Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

## **Regulatory Review & Compliance**

Before any site can enrol patients into the study, the Chief Investigator/Principal Investigator, or designee, will ensure that appropriate approvals from participating organisations are in place, including approval from R&D departments at each of the NHS sites.

For any amendment to the study, the Chief Investigator or designee, in agreement with the sponsor, will submit information to the appropriate body in order for them to issue approval for the amendment. The Chief Investigator or designee will work with sites (R&D departments at NHS sites as well as the PI) so they can put the necessary arrangements in place to implement the amendment and to confirm their support for the study as amended.

## **Amendments**

If the sponsor wishes to make a substantial amendment to the REC application or to the supporting documents, the sponsor will submit a valid notice of amendment to the REC for consideration through the notice of substantial amendment form on IRAS. The REC will provide a response regarding the amendment within 35 days of receipt of the notice. The sponsor will be responsible for deciding whether a proposed amendment is substantial or non-substantial, but either the CI, study co-ordinator or the sponsor themselves may liaise with the REC to obtain advice as to whether a proposed amendment is substantial or not.

Proposed substantive changes will be communicated to relevant stakeholders (e.g. REC, lead NHS R&D, local R&D offices and site PIs) by the sponsor or their representative. The participating sites will then assess whether the amendment affects the NHS permission for that site.

Any amendments that are considered to be non-substantial for the purposes of REC will still be notified to each NHS R&D.

All documentation will be updated to show the most recent version number, thus tracking the amendments.

Guidance will be sought as necessary from the HRA website.

### **8.3 Peer review**

The peer review process will involve review of the study protocol v0.1 by two independent experts. The experts contacted are not employed by any of the NHS Trusts or LHBs involved nor by Cardiff University. Neither reviewer is involved in the study in any way. They have been approached due to their clinical and research expertise, including within the spheres of forensic psychiatry and child and adolescent mental health. One of the reviewers approached works outside the UK, giving an international perspective.

### **8.4 Patient & Public Involvement**

An adult aged male offspring of a mother-patient in a secure psychiatric hospital was interviewed by Pamela Taylor about his views on the proposed research, its acceptability and the design.

### **8.5 Protocol compliance**

Accidental protocol deviations can happen at any time. They will be documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, will

require immediate action and could potentially be classified as a serious breach.

## **8.6 Data protection and patient confidentiality**

All investigators and study site staff will comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles.

This will be achieved specifically by the following safeguards:

- 1) When a participant gives their consent to be interviewed they will be allocated an anonymised code, which will appear on their consent form. For ease of reading, in any subsequent report for publication the participant will be given a false but gender appropriate name for that purpose alone.
- 2) Only the code will be on any other documentation.
- 3) If the participant agrees for the interview to be recorded, then we will prepare a card for the participant to read out, stating their research number, but not name for the tape, and their agreement to being taped. We will ask each participant to refer to other on the tape by their given name only or according to their relationship with the participant, in order to avoid having on the tape any data which would make any other party identifiable.
- 4) The only documentation, which will include both the participant's real name and the related code, will be the consent form and an associated excel document. The consent form will be filed in a locked cabinet at Cardiff University which is separate from the locked store of all the other paper data. The electronic record will also be password protected on a university computer to which only members of the research team will have access.
- 5) All anonymised data generated at the clinical sites will be transported to Hadyn Ellis Building, Cardiff University, where it will then be securely stored in a locked filing cabinet when not in use by a member of the research team.
- 6) Consent forms, which include participant names, will be securely mailed to the university from the site so that personal identification data is never linked with the narrative data during transit.
- 7) If the research team are conducting interviews over several days at a participating site away from Cardiff, then the data generated will be kept at the participating site, locked in a draw or filing cabinet, until the research team member(s) can transport it to Hadyn Ellis Building.
- 8) Any audio tapes with interview(s) on, anonymised in the way described above, will similarly be transported from the interview site to Hadyn Ellis Building by a researcher and will be kept in a locked filing cabinet in Hadyn Ellis Building, apart from when they are being transcribed. As with other study data, they will be kept in this secure location for up to five years.
- 9) The transcription of the taped interview will be conducted by a member of the research team and will be completed at Hadyn Ellis Building. The transcription will be onto a word document, which will be saved under the anonymised code allocated to the participant. The document will be password protected and only

members of the research team will have access. Print outs of the transcribed interviews will be necessary for the process of analysing them, but will be locked away when not being used.

- 10) Any quotations from the participants, which are included as supporting data in any paper submitted for publication or included in oral or poster presentations will be such that the participant's or participant's parent's identity would still be protected. They would be attributed to the false but gender appropriate name given, and any potentially personally identifying information, such as details of the offence, removed.
- 11) During the interview, the interviewer will make notes. The paper on which the notes are made will only have the participant's anonymised code on them. The notes will be transported to Hadyn Ellis Building by the interviewer and securely stored as with all the other data, for up to five years, then securely destroyed.
- 12) The final, fully anonymised dataset will be accessed by the two chief investigators and the research co-ordinator (Pamela Taylor, Sarah Argent and Natasha Kalebic), the named co-investigators and *bona fide* assistants, approved by the Chief Investigator, who sign an agreement to comply with all relevant aspects of this protocol.
- 13) The data will be stored for 5 years after the end of the study and then securely destroyed.
- 14) The data custodian is Pamela Taylor.

## **8.7 Indemnity**

The sponsor will provide insurance and/or indemnity to meet their potential legal liability for harm to participants arising from the design and management of the research. We envisage that the arrangements for the insurance and/or indemnity to meet the potential legal liability of the investigators and collaborators arising from harm to participants in the conduct of the research will be covered by the sponsor on the Cardiff University site (Hadyn Ellis Building) but maybe by NHS indemnity schemes at the NHS sites, however once sponsorship has been applied for we will have clarity on this from our sponsor (it may be that the NHS sites are required by our main sponsor, Cardiff University, to be co-sponsors).

We will also seek advice from the sponsor as to whether they have made arrangements for payment of compensation in the event of harm to the research participants where no legal liability arises.

## **8.8 Access to the final study dataset**

Pamela Taylor, Sarah Argent, Natasha Kalebic, Frances Rice, Janet Parrott and Sandeep Mathews will have access to the full dataset. The final, fully anonymised dataset will be accessed additionally by any *bona fide* assistants, approved by the Chief Investigator, and who sign an agreement to comply with all relevant aspects of this protocol. It is not envisaged that that dataset will be used for secondary analysis.



## 9 DISSEMINATION POLICY

### 9.1 Dissemination policy

The study is being conducted as the major part of Dr Sarah Argent's PhD and will be included in the thesis. Results will also be disseminated in various forms, which are likely to include presentations at the participating centres, presentations at conferences and academic and clinical meetings, and publication in a peer reviewed journal. There is no intention to employ professional writers in relation to this study.

Participants are advised of the plans to disseminate the findings in the participant information leaflet and in the discussion before obtaining their consent we will ensure that they understand this. They are also asked whether they would like to receive information on the results and if so where to send this to them. This will be made available to participants once the results have been published.

### 9.2 Authorship eligibility guidelines and any intended use of professional writers

Any publication relating to the study will have individually named authors, and those authors will have to meet the criteria defined by the International Committee of Medical Journal Editors, namely:

- 1) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND
- 2) Drafting the work or revising it critically for important intellectual content; AND
- 3) Final approval of the version to be published; AND
- 4) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

There is no intention to use professional writers.

## 10 REFERENCES

Argent S, Riddleston L, Warr J, Tippetts H, Meredith Z and Taylor PJ (2017). A period prevalence study of being a parent in a secure psychiatric hospital and a description of the parents, the children and the impact of admission on parent-child contact. *Criminal Behaviour and Mental Health* doi: [10.1002/cbm.2046](https://doi.org/10.1002/cbm.2046).

Chao O, Kuti G (2009). Supporting children of forensic in-patients: whose role is it? *Psychiatric Bulletin* 33: 55-7.

Gow RL, Choo M, Darjee R, Gould S, Steele J (2010). A demographic study of the Orchard Clinic: Scotland's first medium secure unit. *Journal of Forensic Psychiatry and Psychology* 21: 139-55.

Parrott FR, MacInnes DL, Parrott J (2015). Mental Illness and parenthood: being a parent in secure psychiatric care. *Criminal Behaviour and Mental Health* 25: 258-72.

UNICEF (1990). The United Nations Convention on the Rights of the Child. London: UNICEF UK. ([www.unicef.org.uk/Documents/Publication-pdfs/UNCRC\\_PRESS200910web.pdf](http://www.unicef.org.uk/Documents/Publication-pdfs/UNCRC_PRESS200910web.pdf)). [13 August 2016]

## 11. APPENDICIES

### 11.1 Appendix 1- Required documentation

CVs of members of the research team.

### 11.2 Appendix 2 – Schedule of Procedures

Procedures	Preliminary optional meeting with researcher	Meeting with researcher*	Second interview**
Information session (if desired by participant)	x		
Informed consent		x	x
Interview		x	x

\*This would be at least 24 hours after any preliminary meeting where applicable

\*\*This is not anticipated to be a routine occurrence, but we wanted to make provision for any participant who unexpectedly could not complete the interview within one session but wanted to talk to us further and thus meet on a second occasion. Consent would be revisited before commencing the second interview to ensure that this was ongoing but it is not anticipated that a further written consent form would be completed.

### 13.3 Appendix 3 – Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made



**END OF PROJECT PROTOCOL**



**Appendix K: Table showing changes made to protocol v01. in subsequent amendments**

<b>Amendment No.</b>	<b>Protocol version no.</b>	<b>Date issued</b>	<b>Author(s) of changes</b>	<b>Details of changes made</b>
1	V0.2 (following peer review)	15.12.2015	Sarah Argent	<p>1) To add in 'gender neutral' as well as 'gender appropriate' in relation to any false names given to participants to protect their anonymity. This was following a peer reviewer's query.</p> <p>2) We have removed the possibility of the young man whose mother had been a patient in a secure hospital being on the study management group as after further scrutiny of this we had concerns that he may hear information which, depending on what information he has also heard from his parent, may constitute a compromise of confidentiality due to the potentially small number of participants involved.</p> <p>3) Defined the core members of the study management group and clarified the initial previously given on p8. The commitment to an additional clinical member in addition to the PI from each organisation has been removed as there was some concern that the group was becoming disproportionately large. If the NHS REC felt that it would be important to have an additional member then we would be very receptive to relooking at this.</p> <p>4). Added that participants may add any additional comments after the interview by phone or email.</p> <p>5) The addition of direct quotations from the interview with the adult child whose mother had been in a secure hospital to further substantiate and explain how this had directly influenced our study design.</p> <p>6) Additional detail to the theoretical framework.</p> <p>7) Detailed research team members' names from first reference to them and throughout the document.</p> <p>8) The anticipated duration of the project is referred to more than once in the document.</p> <p>9) Additional comment that a copy of the signed consent form will be kept locked</p>

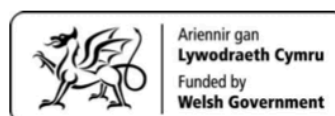
				<p>away at the clinical site, until the original is known to have been received at the university site, at which time the copy will be disposed of securely.</p> <p>10) I have added the involvement of Prof Doug MacInnes and Canterbury Christ Church University.</p> <p>11) Addition of CVs (appendix 1)</p> <p>12) Made provision for seeing potential participants who are in hospital and been explicit about how we would manage this.</p> <p>13) Added that we would meet participants at any designated health care site if negotiable with the service operating at that site.</p> <p>14) Explained why we will not add in a follow up one week later, as suggested by a peer reviewer.</p>
2	V0.3 (following initial request for Sponsorship)	30.01.2018	Sarah Argent	<p>1) Revised wording around the duration of time that potential participants should have to consider their involvement before being interviewed as it was somewhat arbitrary previously.</p> <p>2) Data storage durations were revised to appropriate duration given the research involves the NHS.</p> <p>3) Additional statement is added to the consent form requesting consent for the inclusion of verbatim anonymised quotations from that participant in any publications. This is now also made reference to in the protocol.</p> <p>4) Addition of the sponsor's reference number.</p> <p>5) Removal of reference to the possibility of there being a co-sponsor.</p>
3	V 0.4 (with details of amendments to the interview process)	06.06.2020	Sarah Argent	<p>1) Changed duration of the study to 4 years with an anticipated end date of Spring 2022.</p> <p>2) Changed the study flow chart on page vi to include phone/videoconferencing options for the interview</p> <p>3) On page 4 we have clarified that the visual aids available in face to face interviews will not be used during</p>

				<p>phone interviews or video conference interviews.</p> <p>4) Also on page 4 we have clarified that it will be during the option of face to face interviews that the interviewer would be able to stay with the participant in the unlikely event of any distress. In remote interviews, the interviewer would of course remain available on line/on the end of the phone and this is also stated on page 4-5.</p> <p>5) On page 5 we have added in that the study will additionally generate video files.</p> <p>6) On page 6 we have stated that video files from remote interviewing procedures will be securely stored on university computers and kept for up to 15 years.</p> <p>7) On page 10 we have clarified that for remote interviews consent would be given verbally but that the process of this and the verbal consent itself would be recorded and retained.</p> <p>8) On page 12 we have stated that the study duration is anticipated to be 4 years. This extension is due to both the CI's maternity leave and the pandemic necessitating an amendment to procedure.</p> <p>9) On page 14 we have added reference to the video files which would now be generated in terms of data management.</p>
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## Appendix L: NHS Research Ethics Committee 1 approval letter (20.03.2018)



Gwasanaeth Moeseg Ymchwil  
Research Ethics Service

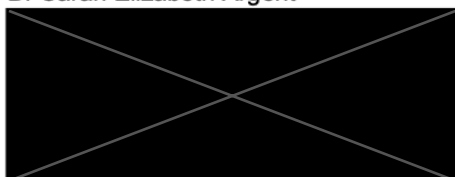


**Wales Research Ethics Committee 1**  
**Castlebridge 4**  
**15-19 Cowbridge Road East**  
**Cardiff**  
**CF11 9AB**

Telephone: 02920 [REDACTED]  
E-mail: [REDACTED]  
Website : [www.hra.nhs.uk](http://www.hra.nhs.uk)

20 March 2018

Dr Sarah Elizabeth Argent



Dear Dr Argent

**Study title:** Exploring the experience of having a parent who is, or who has been, a patient in a secure hospital  
**REC reference:** 18/WA/0073  
**Protocol number:** SPON1657-17  
**IRAS project ID:** 232035

Thank you for your response to the conditions requested in our letter for the above study. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 06 March 2018

### Documents received

The documents received were as follows:

Document	Version	Date
IRAS Checklist XML [Checklist_19032018]		19 March 2018
Participant consent form [Consent Form v0.3 IRAS 232035 (16.03.2018)]	v0.3	16 March 2018
Participant information sheet (PIS) [Participant information sheet v0.3 IRAS 232035 (16.03.2018)]	v0.3	16 March 2018

### Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Project poster for display at clinical sites]	v0.1	15 December 2017

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		15 July 2017
GP/consultant information sheets or letters [Health Care Professionals' Information Sheet ]	v 0.2	04 January 2018
Interview schedules or topic guides for participants [Interview Schedule v0.1 IRAS 232035 (15.12.2017)]	v0.1	15 December 2017
IRAS Application Form [IRAS_Form_31012018]		31 January 2018
IRAS Checklist XML [Checklist_19032018]		19 March 2018
Letter from sponsor		30 January 2018
Other [School experience scale - visual aid to be used during the interview]	v0.1	28 November 2017
Other [Timeline - visual aid to be used in the interview]	v0.1	28 November 2017
Other [Peer Review of Protocol v0.1 by H Putkonen]	v0.1	04 October 2017
Other [Peer Review of Protocol v0.1 (26.09.2017) by H Hales]	v0.1	02 October 2017
Participant consent form [Consent Form v0.3 IRAS 232035 (16.03.2018)]	v0.3	16 March 2018
Participant information sheet (PIS) [Participant information sheet v0.3 IRAS 232035 (16.03.2018)]	v0.3	16 March 2018
Research protocol or project proposal	v0.3	30 January 2018
Response to Additional Conditions Met		19 March 2018
Summary CV for Chief Investigator (CI) [Summary CV for SE Argent]	v0.1	21 December 2017
Summary CV for student [Summary CV for SE Argent]	v0.1	21 December 2017
Summary CV for supervisor (student research) [Summary CVs for Prof Taylor and Dr Rice]		
Summary CV for supervisor (student research) [Summary CV (PJT) 06.11.2017]		06 November 2017

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**18/WA/0073**


**Please quote this number on all correspondence**

Yours sincerely



**Jagjit Sidhu**  
**Manager**

E-mail: 

Copy to:  Abertawe Bro Morgannwg University NHS Trust –  
[abm.rd@wales.nhs.uk](mailto:abm.rd@wales.nhs.uk)

## APPENDIX M: Revised project documents

### Participant information sheet (v0.5 04.06.2020):

<p><b>Will taking part be helpful to me?</b></p> <p>We don't think that taking part will help you as an individual. We hope that the research may lead to improvements for people with similar experiences in the future.</p> <p><b>Are there any disadvantages to me?</b></p> <p>Talking about your experience may be upsetting. If you are upset, the researcher will ask if you need a break, or even to bring the interview to a close. We would ask you to stay with the researcher/stay on line until you feel better. If you want us to contact anyone to help, we will.</p> <p>Unfortunately we cannot pay you for your time. For face to face interviews we can give you the money back for standard class rail or bus tickets, or for petrol if you drive (45p per mile), to cover your travel from home to the interview and back. For train or bus travel you will need to give us your receipt.</p> <p><b>Confidentiality</b></p> <p>Everything you tell us will remain confidential to the research team. This is true unless you tell us that either you or someone else could be at risk of serious harm. Then we would have to tell someone outside the research team, to keep that person safe. If this happened, we would discuss with you who we would speak to and what we would tell them.</p>	<p><b>What happens if I am interested?</b></p> <p>Someone from the research team would be happy to speak with you to answer any questions you may have. This can take as much or as little time as you need. Please feel free to talk to others about the study if you wish.</p> <p>Your choice about whether to take part will not affect your parent's care. You can change your mind at any time - even if you have agreed with the consent form. However, if you have already completed part of the interview, we would like to include your contribution in the research, unless you ask us not to do so.</p> <p><b>How to contact us</b></p> <p>If you want to take part or have any questions about the research please contact:</p> <p>Dr Natasha Kalebic Tel: 02920 688351 (Mon – Fri). Text: 07938 562257 Email: <a href="mailto:gnsh@cardiff.ac.uk">gnsh@cardiff.ac.uk</a> Being the <b>child</b> of a <b>patient</b> detained in a <b>secure hospital</b></p> <p>We hope you will be happy with your interactions with the research team, but if you do wish to raise a complaint about any aspect of the study, please contact Prof. van den Bree, who is independent to the research team. Email: <a href="mailto:vandenbree@cardiff.ac.uk">vandenbree@cardiff.ac.uk</a> Phone: <b>+44 29206 88433</b></p> <p>Alternatively, please contact</p> <p><b>*insert local NHS complaints contact here *</b></p> <p><b>Thank you for reading this information sheet</b></p>	<div>    </div> <p><b>Exploring the experience of having a parent who is a patient in a secure hospital</b></p> <p><b>Participant Information Sheet</b></p> <p><i>Information about our research</i></p> <p>We'd like to invite you to take part in our research. Our aim is to find out about the experience and needs of adult children who have a parent who is, or who has been, a patient in a secure forensic hospital.</p> <p>This leaflet explains a bit about the study and what it would involve. Joining the study is completely your choice. If after reading this leaflet you have any questions please do get in touch with us – contact options are on the back.</p> <p>Prof Pamela Taylor, Dr Sarah Argent, Dr Natasha Kalebic and Dr Fran Rice. Department of Psychological Medicine and Clinical Neurosciences, Cardiff University. Dr Janet Parrott, Bracton Centre, OXLEAS NHS Foundation Trust. Prof Doug MacInnes, Canterbury Christ Church University. Dr Sandeep Mathews, Betsi Cadwaladr University LHB</p> <div>    </div> <p>Participant information sheet v0.5 (04.06.2020) IRAS no 232035</p>
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### **What are we doing and why?**

Maintaining positive relationships with family and friends is really important. One key relationship is that of parent and child. We know that up to half of all patients who are in secure hospitals have at least one child, but we know very little about the children's experience and needs.

### **Who are we asking to take part?**

Anyone aged 18 or over, with a parent (or stepparent or any adult who has cared for you like a parent) who is, or who has been, a patient in a secure forensic hospital. We are inviting people who are currently aged 18+ but it does not matter if you were under 18 years when your parent was admitted to hospital. You need to be fluent enough in English to understand what is being asked of you and to tell us about your experience.

### **What will happen if I choose to take part?**

You will have one pre-arranged meeting, phone or video call, as you prefer, with a researcher who will interview you.

Before the interview starts, the researcher will check with you that you understand the process and make sure that you are happy with all aspects of taking part. If you are, they will go through a Consent Form with you, which we will send to you in advance. This is written confirmation that you are happy to take part. You can also give consent by telling us you agree on a video/phone call which we will record. You can choose whether we record the interview itself or not. You can still change your mind even after you have agreed. Please keep a copy of the Consent Form and this Information Sheet if you wish.

### **During the interview**

The interview will take place at the one of the following places, or by phone/videoconference, whichever best suits you :

- Hadyn Ellis Building, Cardiff
- Caswell Clinic, Bridgend
- Ty Llewelyn, Llanfairfechan
- Bracton Centre, Dartford
- Other clinical sites if preferred, although a site outside of ABMUHB/BCUHB/OXLEAS NHS FT would require the agreement of the site's service provider.

Interviews can be as short or as long as you wish, but we hope you will feel comfortable talking to us for up to an hour. Some interviews may last longer. The important thing is for us to hear everything that you want to tell us. You can ask for a break, or for the interview to stop at any time. We would like to record the interview, but if you don't like that idea, you can just talk to the researcher, who will make notes during the interview.

### **What will I be asked about?**

The researcher will first ask for some basic information, such as your age and occupation. Then the researcher will ask you about your experience of having a parent who has been a patient in a secure hospital. There is no right or wrong response. It is important to us that we hear your story.

The researcher will then ask some further questions to get a complete picture of your experience. Topics will include your own health (including any substance and alcohol use), how things are for you financially, whether you have ever had any trouble with the law, and what, if any, spiritual or religious beliefs you hold. Please remember though, that you may skip any of these questions if there are particular ones which make you uncomfortable.

### **What will happen afterwards?**

All information collected during the research will be kept in locked cabinets in Cardiff University. Any electronic notes, transcripts of the audio files, and video recordings will be password protected and anonymised, again within a university system. We will keep the data for up to 15 years after the study has finished, then it will be securely destroyed.

Findings will be shared with the participating centres listed, then prepared for publication in professional journals. No one's personal details, or any information which could identify them, will be included in any shared information.

If you would like to receive a report of the findings, please tell us and tell us the best way of getting this to you.

### **When will the research end?**

We think that we will have been able to interview enough people (probably between 10 and 20 people) by around Autumn 2021 and as we will be analysing the content of the interviews as we go along, we should be able to present our initial findings by Spring 2022.

### **Who is organising and funding this study?**

Cardiff University and Abertawe Bro Morgannwg University Health Board.




### **Who has reviewed the study?**

An NHS Research Ethics Committee, which has approved it.

<p><b>What are we doing and why?</b></p> <p>Maintaining positive relationships with family and friends is really important. One key relationship is that of parent and child. We know that up to half of all patients who are in secure hospitals have at least one child, but we know very little about the children's experience and needs, and how services could better support them.</p> <p><b>Who are we asking to participate?</b></p> <p>Anyone aged 18 or over, with a parent (or stepparent or any adult who has previously had parental responsibility or cared for them like a parent) who is, or who has been, a patient in a secure forensic hospital. Participants need to be fluent enough in English to understand what is being asked of them and to tell us about their experience.</p> <p><b>What is asked of participants?</b></p> <p>Participants will have one face to face, videoconference or phone meeting with a researcher who will interview them. Participants are welcomed to speak to us prior to this, to discuss any aspect of the research before deciding whether to be involved or not.</p> <p>Before the interview, the researcher will check that the participant understands and is happy with all aspects of his/her participation in the research. If so, then the researcher will ask him/her to sign a consent form, and offer a copy of this and the Participant Information Sheet to keep. For video/phone interviews, consent will be confirmed verbally and the process will be recorded.</p>	<p><b>What would being involved ask of me?</b></p> <p>We are inviting you to think about whether you know of any potential participants. If so, please consider making them aware of the opportunity to participate in the research. If the 'child' is interested in knowing more, then please either give them a 'Participant Information Sheet' or, with their consent, forward their contact details and preferences to Natasha Kalebic (see back page) and we will contact him/her. Please do make the 'child' aware that whether or not s/he participates in the research, this will have no bearing on your involvement with them or on their parent's clinical care.</p> <p>If you are aware of a patient having a child aged 18 years or over, but do not have an existing professional relationship with the 'child', then should you consider it clinically appropriate, we ask you to make the parent-patient aware of the opportunity for their 'child', perhaps by passing on this leaflet, which s/he, in turn, could pass on to the child and/or ask the child to contact us directly if the child wished to do so.</p> <p>Participant information sheets and posters will also be displayed in the clinical sites.</p> <p><b>How to contact us</b></p> <p>If you have any questions or comments about the research, please contact:</p> <p>Dr Natasha Kalebic Tel: 02920 688351 (Mon – Fri). Email: <a href="mailto:gnsh@cardiff.ac.uk">gnsh@cardiff.ac.uk</a></p> <p>Being the <b>child</b> of a <b>patient</b> detained in a <b>secure hospital</b></p>	<div>    </div> <p><b>Exploring the experience of having a parent who is a patient in a secure hospital</b></p> <p><b>Health Care Professionals' Information Sheet</b></p> <p><b>Information about our research</b></p> <p>Please help us raise awareness among potential participants about our research. Our aim is to find out about the experience and needs of adults whose parent is, or has been, a patient in a secure forensic hospital.</p> <p>This leaflet explains a bit about the study, what it would involve for participants, and how we would like staff to be involved. If after reading this leaflet you have any questions please do not hesitate to get in touch – contact options are on the back.</p> <hr/> <p>Prof Pamela Taylor, Dr Sarah Argent, Dr Natasha Kalebic, Dr Fran Rice. Department of Psychological Medicine and Clinical Neurosciences, Cardiff University.</p> <p>Dr Janet Parrott, Bracton Centre, OXLEAS NHS Foundation Trust.</p> <p>Prof Doug MacInnes, Canterbury Christ Church University.</p> <p>Dr Sandeep Mathews, Betsi Cadwaladr University LHB</p> <hr/> <div>    </div> <p>Health Care Professionals' Information Sheet v.0.3 (04.06.2020) IRAS no 232035</p>
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<p><b>During the interview</b></p> <p>The interview will take place at one of these centres or remotely by phone or video conference:</p> <ul style="list-style-type: none"> <li>• Hadyn Ellis Building, Cardiff</li> <li>• Caswell Clinic, Bridgend</li> <li>• Ty Llewelyn, Llanfairfechan</li> <li>• Bracton Centre, Dartford</li> <li>• Other clinical sites if preferred, although a site outside of ABMU LHB/BCU LHB/OXLEAS NHS FT would require the agreement of the site's service provider.</li> </ul> <p>Interviews can be as short or as long as participants wish, but we anticipate that they will be around 60 minutes. For us, the important thing is to hear everything that participants want to tell us. Participants don't have to answer questions and may stop the interview at any time. We would like to record the interview, but this is up to the participant. The researcher will make notes during the interview.</p> <p><b>What will participants be asked about?</b></p> <p>The researcher will first ask a few simple questions to build rapport – e.g. age and occupation.</p> <p>Then the participant will be invited to say anything they like about his/her experience of having a parent who is/was a patient in a secure hospital. Once participants have responded, uninterrupted but with prompts, the researcher will ask some specific questions to build a complete picture. Again, no questions are mandatory.</p>	<p><b>Confidentiality</b></p> <p>Everything participants tell us will remain confidential to the research team, unless we were made aware that someone could be at imminent risk of significant harm. Participants would be aware of this from the consent process. In that event, we would discuss with the participant exactly who could help, and thus who we would speak to and what we would disclose.</p> <p><b>Will taking part be beneficial to participants?</b></p> <p>We don't think that taking part will help participants personally although they may appreciate the opportunity to tell their story. We hope the research may lead to improvements for people in similar situations in the future.</p> <p><b>Are there any disadvantages to participants?</b></p> <p>Talking about their experience may be distressing to participants. Interviewers will be attuned to signs of this and will behave sensitively – for example asking if participants need a break, or bringing the interview to a close. The researcher will encourage participants to stay with them/stay on line until they feel better. If the participant would like us to contact anyone to help them, we will.</p> <p>Unfortunately we cannot compensate for participant's time, but we can reimburse standard class rail/bus fares, or mileage, to cover travel from their home to the interview and back, on production of a valid receipt, if applicable.</p>	<p><b>Who is organising and funding this study?</b></p> <p>Cardiff University and Abertawe Bro Morgannwg University Health Board.</p> <p><b>Who has reviewed the study?</b></p> <p>An NHS Research Ethics Committee, which has approved it.</p> <p><b>What will happen afterwards?</b></p> <p>All information collected during the research will be kept in dedicated locked cabinets in Cardiff University. Any electronic notes, transcripts of the audio files, and video files will be password protected and anonymised, again within a university system. We will keep the anonymised data for 15 years after the study has finished, when it will be securely destroyed.</p> <p>Findings will be shared first at participating centres, then prepared for publication in professional journals. No one's personal details, or any information which could identify them, will be included in any shared information.</p> <p><b>When will the research end?</b></p> <p>The nature of the study means that we can analyse data as we go along. This process allows us to identify categories of relevant information. Our sample is complete when we find no new categories in an interview. We expect this to mean we need to interview 10-20 people. We can't be precise about when this will happen as we are dependent on individuals to want to join the research – but we expect to complete by Spring 2022.</p>
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 <b>CARDIFF UNIVERSITY</b> <b>PRIFYSGOL CAERDYDD</b>	 <b>GIG CYMRU NHS WALES</b> Bwrdd Iechyd Prifysgol Abertawe Bro Morgannwg University Health Board	 <b>Oxleas NHS</b> Improving lives
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## Exploring the experience of having a parent who is, or who has been, a patient in a secure hospital

### Consent Form



**Participant identification number:** \_\_\_\_\_ Please initial box

1. I confirm that I have read the 'Participant Information Sheet' dated..... (version number.....) for the above study. I have been able to ask any questions that I would like to, and these have been answered to my satisfaction. ☐
2. I understand that taking part is completely my decision and voluntary. I know that I can decide not to be part of the study and that this will have no effect on my parent's care. ☐
3. I understand that if I have completed the interview, I can still change my mind about my anonymised contribution to the research being included in the final results, up to 14 days after the interview. I understand though that once 14 days have passed after the interview, my anonymised data will be included in the final results. ☐
4. I understand that the information collected about me may be used to support other research in the future and may be shared with other researchers, or published, but that any information shared would not include anything that would identify me. ☐
5. I agree to take part in the above study. ☐
6. Optional: I give consent to have the interview recorded. ☐
7. Optional: I give consent for the use of quotations saying exactly what I've said in publications, although these will never include anything which would identify that I have said them. ☐
8. Optional: I give consent for my name and contact details to be securely stored at Cardiff University for up to 5 years after the study finishes and to be contacted in this timeframe about new opportunities to take part in related research. ☐

_____ Name of participant	_____ Date	_____ Signature
_____ Name of person obtaining consent	_____ Date	_____ Signature

 <b>GIG CYMRU NHS WALES</b> Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board	Consent Form IRAS ID: 232035 Version 0.4 (04.06.2020)	 <b>Canterbury Christ Church University</b>
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## Appendix N: First order categories grouped according to the broader themes identified and examples of supporting information


<b>Broader themes (in bold with grey shading)</b> First order categories	<b>Examples of supporting data for the categories</b>
<b>Chaos and confusion</b>	
Chaotic	001: chaotic is probably like the perfect word to describe it  between like the ages of 5 and 17 he was like so chaotic you wouldn't believe  normal to grow up in a bit of chaoticness
Confusing	001: you don't really understand the illness you don't understand why they are behaving like they are  you think what's going on? it's a bit confusing  004: Like, if I were to meet my mum, would she even potentially stab me or like, so yeah, it was just quite confusing and we didn't really know like what that meant and like.  005 – mental illness is ... not seen as a thing (cultural) – just a someone being weak .. or.. attention seeking
Weird	001: As a young 'un it was just a bit weird I went there and that was that was really weird  004: it sounds absolutely awful but erm it's weird, it's strange to sort of imagine that that happened. It doesn't feel real even though it was.  005: I know that as a ... professional I should understand that but it's just, you know really weird Erm like he'll (non patient parent) ask me for advice, like it's really weird

Crazy	<p>001: I do enjoy it –[the job] is just crazy... Parents splitting up and having arguments... it's just mental, it's just crazy</p>
Not knowing whose fault it is	<p>005: I don't know whether moving around was her fault or whether it was both of their faults... so whether I'm dyslexic as a result of that travel or I don't know</p>
Being the parent rather than the child (role reversal)	<p>001: he's obviously my dad, but it's like he requires more care than I probably do</p> <p>like with my dad like he's my dad but he's never going to help with me if I had children or whatever its more like the other way round</p> <p>002: I have memories of like me and my brother there would be like cans of beer that we would empty down the sink because we didn't want her to drink it</p> <p>005: I think we were 16-17 when we first went to see her and you know she was mentally you know she was not capable of being a parent so it was like and it was us telling her what was good for her rather than her telling us</p> <p>Like it almost feels like we're parenting her</p>
Not knowing oneself	<p>001: When you're younger and like you're facing all these adversities or whatever and you don't really know what you're good at because you haven't had the support or the parenting that you probably should have had so you don't really know where you fit so it was nice so I've found the job that I'm good at like.</p>
People saying things differently within the family	<p>003: my gran used to say... he... was always spoilt and he was the favourite... but he [father] says things differently, like over the years he's said erm that he was neglected as a child</p> <p>That's mental health and you know he could view things differently and maybe he's been, not make things up but I don't know</p>
Disrupted living arrangements and attachments	<p>001: live with like family members for years, like that's when it's difficult</p> <p>002: Taken by foster carers ...my dad eventually won custody ...lived with my Dad ...went back to [REDACTED] for a couple of years</p> <p>004: physically dragged away and then we were living with, with foster carers</p> <p>005 Dad ... he'd lost everything .... And he took is to [REDACTED]</p>

Lack of control	<p>005 – in hospital... she was asking permission to do anything... she had no freedom to control anything</p> <p>005 – I guess between us and the ward we were asking for their permission to interact with our mum... which was completely different to the kind of relationship we were hoping for.</p> <p>005 – she's going to sheltered accommodation ....I'm slightly worried ... it's only me and my [REDACTED] constantly nagging ....we've had barely any impact on that .. I am not her parent; I don't want to be an authoritative figure in her life</p>
Apart from and different to others 'not fitting in'	<p>004: So, it can feel a bit isolating sometimes that there's always those assumptions about like what parents are supposed to be doing and we didn't fit into that</p>
It being 'mad'	<p>001: It was mad he was in [the secure hospital] for years</p> <p>It was mad how much resources they gave to him</p>
Exposure to parental symptoms	<p>001: he'd be crying and saying I don't know what's wrong with me, I want the voices to stop, all of this kind of stuff</p> <p>He just wanted the voices to stop. So, he would drink and drink and drink</p> <p>he would fixate on things, certain things and he would say things about certain people</p> <p>he was very subdued when he was unwell</p> <p>he was so ill like he couldn't even acknowledge the fact that I'd gone and got him a Christmas tree and loads of lights in order to make his flat look nice, like he would walk round in a circle, or he'd rock back and fore, or he'd get up and go to his bed and then back to the living room, get up and go to bed and then back to the living room. Like, he was really, really scary like, coz you don't know what he's thinking.</p> <p>And then you think like, he could he could hurt me, like he could, you don't know what someone like that's thinking and you know I was in school at that time</p> <p>003: he will go off and talk to himself and it's about like these inventions and things</p>


Exposure to parental symptoms (continued)	<p>004: she had some severe delusions about particularly [celebrity's name] just quite public figures that are out to get her erm and that was sort of the first time that I had sort of experienced any of those serious parts of her sort of mental health coming to play</p> <p>she was starting to get worried that she thought she had a chip put in there that the government had put a chip in her, and she was getting distrusting of sort of doctors and erm just everyone around her and it was getting quite bad</p> <p>as well as having the delusions she was getting really severely depressed and she had a few erm, erm suicide attempts</p>
Being part of parent's delusions	<p>004: she was getting worried about me and my [REDACTED] and our safety and really worried that people were going to come and get us and she'd be saying that she was getting lots of threats that people were going to come and kill us erm and that was quite hard because I think even though we knew we were fine, it was really hard to convince my mum that we were</p> <p>005: every time we started to pick up the phone it would be like 'x, x, you need to like hide, you know they're after you, they're going to get you, you need to run away'.</p>
Parent being drunk	<p>004: she'd be sort of like passed out in the attic and I was probably like three, three years old</p> <p>where she would be like passed out and she'd have sort of bottle of beer there</p> <p>Erm, and the school, she would like come to and pick us up and she'd be clearly quite drunk and she'd be late to pick us up from school</p> <p>so she would come by I remember, sort of drunk sometimes and shouting our names and I remember I would feel really scared</p> <p>005: she passed out drunk she arrived at the door drunk completely red faced and reeking of alcohol.... suddenly arrived at our dad's doorstep, literally drunk</p>



One's own diagnosis being missed	005: I started off in a nurture group erm coz yeah anyway I don't know how it [dyslexia diagnosis] was missed but with everything going on
Severity of parental illness	<p>001: he was just so, so ill I can't even explain it he's got quite serious mental health problems, he's got schizophrenia, which is like horrendous</p> <p>003: he was doing really stupid things, like obviously he was, he needed help, like he wasn't in the right state of mind to be in prison and he did need to be in hospital</p> <p>003: he was out of prison and out of hospital and still really mentally unwell and should have been in hospital or prison</p>
Not recognising parent	<p>005: I just remember the first time seeing her and not really being able to recognise her and my  was like that's mum and I was like what?</p> <p>I literally did not know who she was</p>
Growing up more quickly	001: Like I had to grow up a lot quicker than I should have done
Parental illness being their normal	<p>003: It just seems, I know this is going to sound crazy, but it's been like the norm [parent being in hospital]</p> <p>004: like I try and normalise it a bit more and try and get myself to feel like its normal, because it is my normal</p>
Parent lying to child	004: she'd have sort of bottle of beer there and I'd like ask her what it was and she'd say like apple juice, and I'd try it and I knew it was definitely not apple juice
Other parent denying mental health issues	<p>005: my dad always told us 'there's no mental health problems, it's just her being attention seeking...' I don't think he truly still believes in mental health problems. There's like a lot of denial there about what's happening</p> <p>Being raised by a dad who doesn't believe in mental health issues isn't exactly going to make you think that someone might be suffering from it if you don't believe in it.</p>
Other parent keeping secrets	<p>004: she went to prison, but we didn't know she went to prison and I think my dad tried to keep it a secret from us and said that she went to college</p> <p>I think me and my brother didn't really believe that she was in college, or certainly found it very suspicious. But didn't sort of question it too much</p>

Ill parent saying it was the other parent's fault	005: in a couple of her letters she tried to justify some of the things that happened and put a spin on it that it was our dad's fault.	
Contact being hard and confusing	<p>004: I don't remember how often we got to speak on the phone, but we wrote letters and I remember my [REDACTED] and I would send her drawings that we'd do and things like that , but I remember it was hard and sort of quite confusing</p> <p>005: whenever mum used to visit we'd get super excited, but it always ended up with arguments.</p> <p>005: we can have a proper conversation about some things but she can't recognise the flaws in herself and it boggles me, I can't understand why</p>	
Impact of parental self-harm/risk to self	<p>003: I remember something sticking in my head where he either scalded his own hands or he'd done something with hot water and that's when they put him into secure hospital</p> <p>005: I know the last time she was to be stepped down from medium to low security she tied a ligature and erm obviously it didn't work they cut her down</p>	
Dissonance	Wanting a normal parent-child relationship (second order category)	<p>004: like I really wish... we could just like have a normal relationship</p> <p>005: it's kind of gone from us wanting a mother in our lives</p> <p>I still kind of in a weird way want that happy family that I wanted as a child</p> <p>To an extent I still want her to be my mother</p> <p>Maybe it's me still wanting her to be a parent and take the onus</p>
	Not wanting parental role over parent (second order category)	005: I don't know how much responsibility I should feel for her making the right decision because I'm not her parent, I'm not her father I don't want to be an authoritative figure in her life

		<p>Wanting her to be a parent.... So I don't have to be that kind of figure</p> <p>A lawyer... wrote to my sister and asked whether either of us wanted to take power of attorney and I've never, well to be blunt I just outright refused. We didn't want that responsibility over her. ... it felt wrong at that time to take that responsibility over her</p>
	Wanting a normal parent-child relationship (second order category)	<p>004: I really wish ...we could just have a normal relationship</p> <p>005: it's kind of gone from us wanting a mother in our lives I still kind of in a weird way want that happy family that I wanted as a child</p> <p>To an extent I still want her to be my mother</p> <p>Maybe it's me still wanting her to be a parent and take onus</p>
	Being pushed into contact with parent (second order category)	<p>005: my sister really sort of pushed me to do it erm to start speaking to her regularly, to like go down and see her</p>
<b>Memory problems</b>		
Experiences not feeling real on remembering	004: so that, yeah that looking back on it sounds absolutely awful but erm it's weird, it's strange to sort of imagine that that happened. It doesn't feel real even though it was.	
Struggling to remember	005: I struggle to remember her birthday	
Lost memories	<p>001: And I don't remember him before he was ill anymore, I used to be able to when I was younger but I don't remember him before he was ill.</p> <p>003: I don't remember a lot from when I was young to be honest</p> <p>004: some of my memory is a bit sketchy</p> <p>I mean, I'm pretty sure I remember this but obviously memories are like pretty sketchy</p>	

Surprise at remembering	003: I don't even know how I remember all this
Vivid memories	<p>003: something that sticks in my head</p> <p>004: I just remember they had lots of arguments when I was young (wider context suggested this stuck out)</p> <p>I remember quite vividly, there was one point where my mum was drunk at that point ... and then our door got broken down by the social workers that came ... but I remember them knocking and then my mum screaming don't take my children away</p> <p>005: my earliest memories are of my parents when they were together, arguing</p>
Experiencing flashbacks	005: occasionally I get flashbacks where it's like I'm 4 and my  is like 3 or 2 and my mum was passed out
Second hand memories – things participant has heard	003: regarding remembering: just vaguely and I don't know whether it's from things I heard my grandmother say. I don't remember any of it as such but it's remembering things from what my grandmother has maybe told me.
Holding on and letting go of memories	001: I used to write in a diary too. I've got a diary which is like hidden away which I'm never ever opening again but I've still got it, I can't get rid of it, and the diary has got loads of stuff written in it
<b>Difficult emotions</b>	
It feeling horrible	001: I used to leave [school] on lunchtime, walk to his flat stay and have a cup of tea and go back to school. It was horrible.
Feelings of loss	<p>005 – I came to accept that I was never going to get that happy family that I wanted</p> <p>005 – she arrived ...literally drunk ...but it didn't matter at the time, it was like 'yay, out mum's back' .... I guess that was the last time we had that sort of innocence</p> <p>005 ...it was her emotions were very blunted .. not the mum we were used to</p>
Feeling hard done by	001: you just feel a little bit like hard done by
Worrying about parent	<p>001: I'd always worry that he would hurt himself. Always.</p> <p>He'd be on his own and I'd think oh my god I could leave here now and he could just go and like kill himself. It was horrendous...</p> <p>we're just thinking like he's [father] dead...</p> <p>every now and again my dad will slip off the rails and do something stupid and that's when I worry about him</p> <p>004: we eventually found out and was really worried</p>

Feeling guilty	<p>004: and I think I just didn't really know how to support that and I felt sort of, a lot of guilt</p> <p>I think x and I often felt sort of guilty because it often, we'd be quite inconsistent with how often we'd speak to her</p> <p>I think it's that guilt of maybe I need to be making these calls to the hospital more to be letting them know what's happening.</p> <p>005: then like on one hand we felt really guilty</p> <p>So there was a degree of guilt</p>
Felt s/he was being held hostage/trapped	<p>005: I don't know we felt like we were held hostage on the phone</p> <p>We're kind of trapped with the phone</p>
Feeling shocked	<p>004: I was really shocked by it [parent's illness] erm and she went into hospital not too long after that</p> <p>005: I think her size and the fact that her skin and hair were completely different was a massive shock</p>
Developing anxiety	<p>005: you know in a way I started developing like I don't even know if there's a term for it but almost like an anxiety about answering the phone</p>
Feeling miserable	<p>005: me and my [REDACTED] just felt miserable (after contact)</p>
Feeling apathetic	<p>005: I tend to be in that apathetic state</p>
Wanting it to stop	<p>001: ... you just want it to stop</p>
Not what we were hoping for (disappointment)	<p>005: like God this is you know, this is not what we were hoping for (reality of visiting parent)</p>
Anger at parent	<p>001: he'd never normally ring me if he was drunk coz he knows I'd go mental</p> <p>It was horrible and I was so angry with him, coz like why was he so selfish?</p>
Resenting parent	<p>003: There's been times when I've sort of resented him a bit as well... he was off his face on drugs.... And he'd crashed literally just outside my comprehensive school and I remember thinking like why? You know? Like I know it wasn't about me but you're thinking like why do this to me outside my school, you know this is my school</p>

Resenting parent (continued)	005: whenever I think about the way in which my mum let herself go does it does bring back an edge of resentment and in a way I kinda use that as a way to push myself out of her life
Blaming parent	005: I've kind of always held it in myself that I've always blamed her for the way things turned out  My mum's actions in terms of like the smoking and the drinking actually led to us being in foster care for 6 months to a year
'Heart break' 'heart ache'	001: it's just heart breaking to see someone like that, you know, he was just so, so ill  it was just so heart breaking to see. [him unwell]  003: I'd see the heartache they [grandparents] would go through
Dreading	005: It kind of got to the point where we kind of like dreaded answering the phones
Feeling frightened [of parent's presentation]	001: It was frightening  he was really, really scary like, coz you don't know what he's thinking. And then you think like, he could, he could hurt me  I had my first ever boyfriend and my father said to me erm, er 'I'm going to kill [REDACTED] and I know exactly where to bury him'.  004: and I remember x and I would feel really scared that we just we you know just feared our mum a bit at that point (when she would be calling for them outside the house)
Feeling scared	004: my [REDACTED] and I were just terrified and we just ran and my [REDACTED] hid (when social care and police came to remove them from mother)  I remember being quite scared sort of at that age, just think anyone who has been in prison is a bad person and it was hard ,and then I felt really, really bad for her  I remember getting a text saying that she'd stabbed someone, and she was potentially going back to prison. And I can't really remember - I just remember ,I think I was 16,17 at this point, just being really scared and I don't really remember the timeline I just remember getting that text and speaking to my mum and then I think there was a court case that went on a while and I don't think she went back to prison. I think she went straight to a secure hospital
Feeling emotionally exhausted	004: it was just emotionally very exhausting

Lonely	<p>005: I have memories of being in the house alone or just with mum from the age of about 4</p> <p>001: you're feeling a little bit lonely and isolated</p>
Wanting to avoid [parent]	<p>005 dreaded answering the phone ....every time ... 'you need to hide, you know they're after you ...' I started developing ... like an anxiety about answering the phone</p> <p>Every time I'd see her name [on the phone] I'd want to ignore it'</p> <p>005 – [also avoidance as a strategy] during exam times I'd just go almost into a hermit... you can't have a five minute chat with my Mum it'll be an hour and a half or two hours ...because she'll say 'bye' and then straight away ask another question....</p>
Feeling embarrassed (especially when younger)	<p>001: I was so angry with him because it was embarrassing and I just wanted to come home and not have to have a drama and not have to worry and all that kind of stuff</p> <p>To be honest I used to hide it from everybody, I was so embarrassed as a kid and I was literally like I wouldn't bring people over if he was ill</p> <p>003: sort of like when he was out [of prison/hospital] I think dreading bumping into him when I was out with my school friends and things in case he was embarrassing because he was on drugs you know?</p> <p>005: so there was a ... degree of embarrassment</p> <p>There was a lot of embarrassment initially at sort of seeing her</p> <p>I still felt really embarrassed initially like walking around town with her</p>
Feeling under pressure	<p>001: It's hard the pressure</p> <p>004: but there's also a lot of pressure I think from that where if we're the only reason she's alive, it's, it's sort of a lot.</p> <p>005: when she would relapse... when me and my sister had taken like the least interaction (doesn't say 'pressure' but the pressure was evident)</p>

Stability, security and autonomy	
No longer embarrassed as an adult – being more open	<p>001: I'm a lot more open about it now I'm not embarrassed at all about it because it's not his fault</p> <p>005: at the end of the day you have to think like it's your mother, she gave you life, why would you be embarrassed to walk around with her?</p>
Knowing one's own boundaries as an adult	001: things I'll tolerate and then there's certain things that I won't
Finding oneself	001: When you're younger and like you're facing all these adversities or whatever and you don't really know what you're good at because you haven't had the support or the parenting that you probably should have had so you don't really know where you fit so it was nice so I've found the job that I'm good at like.
Wanting a career and own home – aspirations (self-identity)	<p>001: Like I wanted a career and to be a professional in a career that I couldn't like just be sacked from</p> <p>I just thought I'm sick of this I just want my own home. And I've got my own house now</p> <p>I could leave now and get a job but I don't want to do that because I know I want to be a professional</p>
Feeling fulfilled	004: Yeah, I really love it, it's really interesting. That's the sort of feeling that I was looking for in teaching that I didn't get - the like, you wake up in the morning and you feel like I'm being stretched, you know, you can see the difference you know that I'm making and the problem that I'm trying to solve – well you definitely see that in teaching, but it's like sort of more, sort of intellectually stimulating, like I guess with teaching it's really exciting, it's never dull, but it becomes a bit operational to an extent, so yeah I'm really enjoying it .
Independence/pride in achievements <i>Leading to self respect and identity self-worth</i>	<p>001: but I did do it all myself like I had three jobs when I was in Uni, I worked my arse off</p> <p>I feel like I'm in a really good position and I know I did it, I did it myself like. And I can confidently say that</p> <p>I thought what am I doing so then I worked really, really hard and ended up leaving school with 13 GCSEs</p> <p>I feel like I've actually found a job that I'm good at and that people think I'm good at.</p> <p>004: I'm really happy, really sort of proud of what I've done and achieved and what I'm doing now</p>



Looking back and thinking other family members had mental health problems <i>Finding meaning in past experiences</i>	004: I didn't really understand back then but now I think she (grandmother) probably suffers from quite a few sort of mental health sort of problems that have never been diagnosed  looking back now I think my dad probably had like some sort of social issues as well which made it complicated that they couldn't really like speak together, I'm not sure what I'm trying to say, I think it was just complications with both parents
Parent recovering – degree of normality [mostly to contact]	001: he was coming around 005: She was excited and happy and the phone calls with her from that point weren't as bad (as in easier for the offspring)
Relieved In control	001: I felt relieved that it was now my own choice to go and see him and then walk away I didn't have to see him out in the community pissed Now I'm an adult, I can say what I want
Feeling happier	001: If we talk about the present day, I felt much better about it  But now I'm older it's just like I feel more like I'm more happier
Speaking more about their situation as older	001: I'm a lot more open about it now, I'm not embarrassed at all about it because it's not his fault, he didn't wish for that. But as a child you don't want your friends and everyone knowing about that.  004: I still don't talk about it loads, but I'm a lot more open if that makes sense
Relief at parent being in secure care and being safe	001: I know he's safe. the best thing that ever happened to him. I know he's safe every night I always left there feeling that he was safe I always left there feeling like I knew he was alright that was the first time I felt happy about him receiving care  The fact that he was locked away and couldn't leave, I felt relieved, I felt relieved that it was now my own choice to go and see him and then walk away I didn't have to see him out in the community pissed, do you know what I mean like, I wouldn't have to see him, I didn't want to wake up one day and him to like kill himself. I knew that he was like safe so that was nice.

Relief at parent being in secure care and being safe (continued)	<p>003: I sort of had that peace of mind ... thinking well yeah he's not around the street, he's not on drugs, he's not going to cause harm to himself or anybody else, it was yeah a benefit when we knew where he was and what he was doing</p> <p>004: it helped knowing that she was somewhere where she was supported, and I think it was a big relief ... yeah there was a relief and sense that she was being looked after but the other part was obviously she knew that she needed to be there, obviously she'd rather have had her own freedoms</p> <p>005: 'as long as she's safe at that point that's all we can hope for'</p>
<b>Active resolving strategies</b>	
Hope for parent's future	<p>003: but now, I see like he wants to get better... he seems different this time round.</p> <p>But like I said it feels like he wants to get better and it feels different and he's more positive and he you know says everything right that I think he should be saying</p> <p>004: She's now actually, I didn't tell you, she has gone into supported accommodation. Yeah, it was a huge moment and we were like 'no way' and I'm really, really happy for her and I think they have got the transition period sorted and she has a lot more freedom and is like cooking her own meals so yeah that's been super, super positive and something I guess I wasn't sure if it would happen or not over the last 7 or so years.</p>
Benefit finding/strengths from the experience Seeing the positives	<p>001: I wouldn't be able to sit here now and talk about this or talk to the children I work with the way I do if it hadn't happened</p> <p>005: being a bit more careful financially Budgeting – we had a single parent growing up in relative poverty</p>
Non self-blaming	<p>001: No, I knew it was my parent's fault I think I would have had to put a lot of blame on my Dad.</p>
Sharing/talking	<p>001 :Talking to Nan [father's mother, who knew father and his problems well] so we'd be experiencing the same thing [as distinct from mother] I talked to my friends .... But obviously they don't know what to say at that age</p>

Sharing/talking (continued)	002: I remember telling my [music] teacher ... she was sort of my closest adult ....the school got me a little bit of counselling ....
Reflecting	004: I think one of the biggest issues that I've sort of reflected on, I think one thing that my mum's found particularly tough is sort of not having a support network.
Trying for control	005 – [after a long speech on how mother's illness is always blamed – no responsibility – and her need to be seen as a good Mum and some concessions towards that, but how difficult after what he has experienced] I guess I'm trying to control how it affects me 005 – I feel like I'd let it control my life in a way where it's constantly having to make her decisions for her ... [also responsibility]
Wanting to do things differently to parents	001: I know for a fact that I'll never let my child be exposed to that. I always say to [my partner] when we have kids I'm never going to argue in front of them, they're never going to have to choose and they're never going to go to school and worry about what they have to come home to. Do you know all of that kind of thing I always think like I'm never going to let that happen.
Not giving up	001: I did my A levels in sixth form and failed my first year and I thought I'm still not going to give up  so I decided I wanted to do the masters erm but I went to the interview and didn't get on the first time didn't get into [REDACTED] university that first time. I thought right I'm going to do it again  so I did another year of volunteer work and went back the next year and went to [REDACTED] and [REDACTED] and got in to both and I was landed, I couldn't believe it  005: trying really hard to get to [university]. I always feel that I have to work a bit harder but I never let that get you down
Being thankful	001: Like my life could have been so different to what it is now  005: I guess I'm really thankful in this respect that she's somewhere there's help available with money and financially as well as medication and so she's provided for in a way that she wouldn't be if she was say in [REDACTED]  My dad came back and had to go to court to get custody of us which I'm really thankful for now... because we could have ended up being very different people

Participant being proud of the parent	005: she's lost like 10kgs in the last 3 months so I'm proud of her in that respect
Acceptance	005 – to an extent I still want her to be my mother, but I've accepted it probably won't be the same
Affection/love for/warmth towards parent	001: he's such a nice person and he'd do anything for anybody he's the kindest person I know  004: even though we still sort of loved her at that point we were just really scared
Resuming contact (voluntary)	001: when he went to [REDACTED] that's when the contact started back with him and that was really nice because he had all the help he needed
Voluntary contact	001: and I go and see him as much as I can
Stepping away	001: I had to step away and not talk to him, I had to just leave him alone so I had to not talk to him for quite a few years then, me my mother and my brothers, didn't speak to him  when I stopped talking to my father I must have been about 14/15  I chose not to speak to him and that's when I didn't speak to him then until I was about 17/18. So about 2 or 3 years maybe, something like that. So that's what it was like at that point.  005: I started avoiding any, any number  I was still more anti trying to get back into her life
Seeing a changed understanding and awareness (developing a wider perspective)	001: and when you're younger you just think oh they're not very well and they've gone away for a couple of weeks  and I look back and think like oh my god like how were social services not involved.  I think now I'm much more like understanding and reflecting  004: and I think what I understood as a child is very different to what I understand now  I sort of knew some of the details as a child but I wasn't really aware of the extent of it

Seeing a changed understanding and awareness (developing a wider perspective) (continued)	<p>I think looking back now I think I didn't really understand back then</p> <p>I think at that point as children we didn't really erm, I guess we obviously couldn't appreciate the complexity of it</p> <p>At the time we sort felt like our dad was our hero who saved us and our mum was a bit of a villain I guess to put it really, really simply</p>
Not remembering – blocking out	001: with children, you know when they're exposed to trauma they forget a lot and can't tell you. You know I can't remember my childhood I can't remember what it was like to be age like a young child, to be aged 8, 9, 10. I don't remember anything. People talk about, oh like when I was a kid, me and my friends did this, but I don't know, I couldn't tell you anything. I don't remember anything. It's like a part of me has subconsciously made the decision to, I just need to like block that out
Family member corroborating experiences	004: I'm pretty sure I remember this but obviously memories are like pretty sketchy. But my [REDACTED] has agreed that they happened
Not feeling sorry for oneself	<p>001: You know I'm not going to sit here like and feel sorry for myself.</p> <p>I don't sit there every day wallowing in pity</p> <p>005: I always feel that I have to work a bit harder but I never let that get you down</p>
Sense of responsibility /protecting others from parent	001: I was happy to take the worry on me... but I can't do it to someone else [so she stopped seeing father]
<b>Inherent strengths</b>	
Resilience	<p>001: I'm very resilient and I don't even know how that happened because I didn't have any support</p> <p>I just feel like I'm resilient</p> <p>004: I also think I can handle change erm quite easily now, like nothing can shock me I feel and actually that is a really, really important skill. Yeah, having the resilience to, you know, I appreciate what I have now, but if things were taken away from me or anything changed then I feel like I'd be able to cope with like that</p>

Resilience (continued)	005: things like resilience, erm where it's you know like we've not had the bet cards handed to us growing up and we had to be a mixture of resourceful and resilient to push through
Being empathic	004: I think I'm able to be a lot more empathetic in people in a lot more different situations  005: empathy... I would always volunteer because I felt I could like empathise with them (people with mental disorder(s))
Being resourceful	005: being a bit more resourceful We had to be a mixture of resourceful and resilient to push through I guess we ended up being not wasteful and became a bit more resourceful
Being sheltered	003: maybe I was sheltered a lot from what went on  I was very well protected... I erm had good holidays, good experiences
Being cared for by grandparents	003: My grandparents brought me up  I had a really good upbringing from them
Solidarity with sibling	004: my [REDACTED] and I were together erm for the whole time, which yeah, I think it would have been really tough to not, to have been separated 002: So, I kept that to myself and was sort of quite secretive about that. But no, I had my [REDACTED] and we would speak about it, but there weren't any adults I spoke to.
School being one's own – finding refuge (separate to family home)	001: My school was a break, like school was the best thing ever for me coz I could actually just relax and not worry about whatever was going on at home.  003: you know this is my school (as opposed to father's)
Sense of affection/love/warmth from [unwell] parent	004: we always felt like very loved erm by my mum, erm she really cared for us and really tried the best that she could  she's super loving erm she cares about us very, very much and I think she'll often tell us that we're like the reason she's still alive erm and that's you know, it's really nice
<b>Barriers</b>	
Hiding identity	003: going over to friend's houses and making new friends in comprehensive school and going over and ... I'd automatically I'd be like, I live with my grandparents and I'd give my grandparents' names like sort of hiding.

Other parent badmouthing and blaming unwell parent	<p>005: I don't think my dad meant to bad mouth her but I don't think he could well, he'd say you can't trust your mum to do this, you can't trust your mum to do that and it just kind of ate away at us</p> <p>My dad kind of blamed her</p>
Parent not having anyone for support and being isolated	004: I think one of the biggest issues that I've sort of reflected on, I think one thing that my mum's found particularly tough is sort of not having a support network. Erm, she didn't get it from her father, her mum was very unreliable, and her siblings were you know sort of one's not there anymore and the other one was I think she went missing for a while erm and she just didn't have anyone, like very little friends
Awareness of publicity around parental actions	<p>003: I know there was a newspaper article about it and I'm not sure if I've got the cutting in the house</p> <p>It was sort of public you know we lived in a little town and if anything happened it'd be publicised and everybody would know</p>
Unheard (as a child)	<p>001: I think people just thought that's how it is you know? I don't think people really listened or paid attention or read between the lines when I was saying things.</p> <p>'in the letter I actually wrote about everything that was going on at home, like that I was afraid to go home, and I remember writing about my dad [the unwell parent]. And I put it in the box, and I was hoping someone would read it but no one ever did ... and I never did anything after that.'</p>
School not taking action/not listening/not safeguarding	001: 'in the letter I actually wrote about everything that was going on at home, like that I was afraid to go home, and I remember writing about my dad [the unwell parent]. And I put it in the box, and I was hoping someone would read it but no one ever did ... and I never did anything after that.'
Polarisation/ black and white thinking	<p>002</p> <p>Dad was our hero who saved us and our Mum was a bit of a villain</p> <p>005 – I kinda sided with him [Dad] a little bit</p>
Other people not able to empathise	<p>004: most people can't really empathise with it</p> <p>people can't relate to it</p>

Other people not able to empathise (continued)	<p>like I can't be bothered to bring this up because it's going to take a lot of explaining and people are going to be awkward and uncomfortable even though they're perfectly nice about it</p> <p>people not being able to empathise</p> <p>when people haven't had a similar experience, I feel like they wouldn't be able to help with some concerns or issues that I might be feeling</p>
Ambivalence around talking to people about experience	004: I think it was my [music] teacher and she'd ask me questions after that and I felt I could talk to her but I don't really, I feel like part of me at the time, I don't think I feel like I needed to or wanted to, even though looking back now I think part of me feels that that would have been really helpful, but no and I think even my dad like we didn't really speak about it very much
Not knowing how to help/support parent	<p>004: I didn't know if I was saying the right things</p> <p>I think I was just yeah, I had no idea how to help or be there.</p> <p>I didn't know what the best things to do for me to support, or what was expected of me, and I wonder whether again that's part down to erm that we weren't in my mum's care. I wonder if the conversation would have been different there.</p>
Limited family support	<p>001: I have really limited family support</p> <p>some people have got really supportive parents who are always there for you and I haven't really got that</p>
Being isolated	<p>001: you're feeling a little bit lonely and isolated</p> <p>004: So, it can feel a bit isolating sometimes that there's always those assumptions about like what parents are supposed to be doing and we didn't fit into that</p> <p>Like I don't know, it always felt like our relationship was very different to our friends, and even though I was comfortable talking about it with my friends, you know, when people say casually you might get asked by your teachers 'oh what does your mum do?' You know, that's like a question 'what do they do?', 'oh well my mum's just in hospital'. So, it can feel a bit isolating sometimes that there's always those assumptions about like what parents are supposed to be doing and we didn't fit into that</p>



Language barrier	005 – going to [REDACTED] where I couldn't speak a word ..... And on my Mum's side everyone's pretty much dyslexic
Chemical separation/separated by the illness/treatment of the illness	001: getting his injections and being comatosed
Separated (forced)	<p>001: I couldn't actually go and see him and couldn't talk to him you can't go there [PICU in MSU] as a child without an adult,</p> <p>003: (maybe not forced separation) he moved from there to x [a high secure hospital] I never went there but I spoke to him whilst he was there</p> <p>004: we were just physically dragged away and then we were living with, with foster carers</p>
Participant being secretive with other parent (well parent)	004: I didn't tell my dad that I'd told anyone else or that I went to counselling because I felt like at the time my dad wouldn't understand so I kept that to myself and was sort of quite secretive about that
Lying to parent (to protect them)	005: she'll ask me and my sister 'was I a good mum'? you know we have to nod along and smile and just say 'yeah'.... I don't have the heart to tell her you know you nearly let my sister burn down the house and probably kill all of us inside it
Other parent not understanding participant	<p>004: sometimes he takes quite a hard line and doesn't understand the decisions that we make, which can be quite hard sometimes</p> <p>I felt like at the time my dad wouldn't understand</p>
Not wanting to burden people	<p>004: yeah when things are quite tricky I still think that sometimes I either suppress when things are tricky because I don't want to burden people with it</p> <p>I didn't want to feel that I was burdening the hospital or ask too many questions</p>
Awareness of own genetic vulnerability to mental illness	<p>004: So, it's on our heads. We know that we're like genetically more prone, but I think that we understand that a huge part of it is environmental and we have a pretty, a very, very different upbringing to what my mum had so we're in a very different position</p> <p>I think maybe I shouldn't tell you this but my [REDACTED] and I said oh well you know schizophrenia is part genetic so we said we'll if we get to 30 and we don't have schizophrenia we should have a party so sometimes I think I might be overthinking it and I think oh maybe I'm slightly bipolar or maybe I'm this, but I think generally I'm absolutely fine. But erm I do have several</p>

Awareness of own genetic vulnerability to mental illness (continued)	weeks where I'll be like in the best mood ever and then suddenly feel a bit low, but I think that's probably quite normal and it's not actually something that I'm concerned about
Wanting to ignore it	005: every time I'd see her name [on the caller ID] like in the back of my mind I'd want to ignore it and initially I didn't and then as, as it kind of kept going on and on and on, erm and at the time being quite young still I just kept ignoring my phone
Familial/genetic element to illness	005: from my mum's side, her whole family deals with at least depression... one of her brothers committed suicide... so I think from her side it's quite sad because it seems to be quite a familial thing  On my mum's side where everyone's pretty much dyslexic and I'm pretty sure my dad's dyslexic
It being tough	005: Erm, it was like, it was quite tough, and then with like the impact of my mum  From that regard it was quite tough because after that any number ... that I'd never seen I started avoiding  It's really tough to try and have it constantly on your mind
Feeling hungry	005: I don't know that's where my almost prisoner's eating complex comes from – I just like block off my food and just rush it down – stems from when we were really hungry as kids and now like when we have anything I just finish it in one sitting
Being critical of the well parent/other parent	001: (multiple extracts) including: My mother wasn't great I've got to be honest with you, she wasn't great through this at all.  she couldn't be there for me because she had to be there for herself  004: looking back now I think my dad probably had like some sort of social issues as well which made it complicated  I felt like at the time my dad wouldn't understand  005: thinking about it now it was the worst decision he's ever made
Readmission to secure hospital	001: I think he'll end up back there, coz he can't, he erm he can't last very long  003: I remember it being an ongoing thing when he would come out for brief times and then he'd be going back into secure facilities again

Readmission to secure hospital (continued)	<p>He'd get released, he'd get like a new flat and my grandmother would be helping him set it all up and things would go downhill again... and he'd be back into a secure facility again and that's just been a spiral over the years</p> <p>He would do what he was told to ...come out again... and then he'd be left to his own devices and then he'd go back down the same road again.</p> <p>005: every time she gets freedom she'll kinda self destruct and it ends up her going back in to a secure hospital</p> <p>The last time she was to be stepped down from medium to low security she always ended up doing something which resulted in staff completely reconsidering</p>
Cycles/circles re physical health although about ability to mentally engage in change of behaviour	<p>004: really frustrating and we put a lot into we're going to help her get through this, she definitely can do it and then she'll try and try and try and there have been so many circles of this happening</p> <p>005: because of her track record I just see it going badly</p>
Ups and downs in parent's mental health	<p>004: there were lots of up and downs</p> <p>there were lots of ups and downs and I think by the time she got to the there'd been lots of ups and downs and there'd be points when she'd be doing really, really well erm and she'd have like really good days and we'd like speak on the phone and she'd be really positive and then there was one point when the delusions were getting really, really bad</p>
Things getting worse	<p>005: every time you spoke to her on the phone, initially it was quite pleasant but then as the years progressed it got worse and worse as her mental health started to take a hit</p>
Fading hope – change in optimism	<p>004: there was a lot of hope, I think in the early stages, that things would just you know she'd be fine and and, and everything would be okay but there were just so many so, many ups and downs</p> <p>005: the other aspect is trying to, well getting to terms with the mother child relationship was off the table</p>

Absence of being parented	<p>001: he's not really like a dad</p> <p>like with my dad like he's my dad but he's never going to help with me if I had children</p> <p>003: he's always been in my life and not in another sense</p> <p>005: she wasn't there when we were young, she wasn't there, even though physically she was there I don't think mentally I don't know what was going on</p> <p>the other aspect is trying to, well getting to terms with the mother child relationship was off the table</p>
Wishing parent was better	004: there were times when I remember just thinking oh like I really wish my mum would just be better
Parental change subsequent to illness	<p>005: she was quite sedated... she'd reply when we spoke to her but she wouldn't really instigate conversation.... Her emotions were very blunted which was you know not the mum we were used to</p> <p>I think her size and the fact that her skin and her hair were completely different was a massive shock</p>
Parent institutionalised	<p>001: I think he's very institutionalised. So I know and that unfortunately that's the bad thing about that isn't it, those kind of places</p> <p>I think he just can't cope on his own like</p>
Throwing blame around	005: You can throw blame anywhere you like but it doesn't change anything and it's not productive
<b>Experience of health and social care professionals</b>	
Anticipatory fear of secure hospital being scary	<p>001: all I knew was he was in [secure hospital] and it was a mental health hospital and it was a bit scary because you hear that [secure hospital] is like they've got certain parts of [secure hospital] which is all like really, really like prolific offenders, like murderers, all this stuff people tell you like, and you think Oh my god that's a really scary place</p> <p>003: you know thinking about if [participant's daughter] had to go and visit someone in a prison or hospital it's quite daunting</p>

Secure hospital scary	001: they could make the facilities more friendly and more open. Because they're not really that friendly and open really are they, they're quite scary
Secure hospital not being scary	<p>001: then I went there and it looks like an office. Laughs. It's not scary at all</p> <p>003: I do remember going to visit my father in prisons and secure hospitals, but it was never a bad experience</p> <p>I remember going there when I was young and being able to walk around the grounds and it being a nice area and I remember having a nice visit with him</p> <p>For me, my memories are not what you'd think... they're not scary. I remember there being like a little soft play area with toys for children and I remember there being like a little café sort of area where there was sort of like an older lady serving fresh cakes and cups of coffee and tea and things and I just remember sitting round a little table and positive, it wasn't scary or horrible experience in the prisons or the hospitals that I can remember going to.</p>
Impersonal care (outside secure estate)	001: they don't know him it's okay, but it's not personal
No assertive care outside secure services	003: I remember he never used to take his medication and when my grandmother used to question it they'd say well you know it's up to him we can't force him to take his medication
Taking charge (when services not meeting expectations)	<p>001: So, I rung the agency and I was like my father's drunk and they were like 'oh my God, is he?' and I was like 'yeah he is, do you not check him do you not look in on him?'</p> <p>I'd take him like his favourite food and pop or whatever</p> <p>I'd meet him outside at the bus stop take him in to town have a cup of tea and it was consistency for him</p> <p>004: me and x we would be like cans of beer that we would empty down the sink because we didn't want her to drink it</p> <p>005: my x was running around... setting fire ... and I had to like, I just smelt smoke and grabbed everything I could and put it in the bath tub and turned the shower head on</p>

Staff not preparing offspring for reality	005 – we weren't told the changes that had happened .... Asking them to prepare a ten minute conversation to prepare you beforehand seems impossible (knowing what I know now from a health worker perspective) but it would have been nice to know what was going on
Good resources and support in secure hospital	001: he had all the help he needed. He had therapies he had everything  004: I think my mum's consultant explained it really well
Not knowing (poor communication from secure hospital staff)	004: I don't really remember, and I could be wrong, but I don't sort of remember speaking to a member of staff or anyone to explain what was happening  I wonder whether the hospital, whether they could have taken a more proactive approach to involving me and my brother.  I guess hospitals don't want to assume that people can do more than they can, but I would have appreciated just knowing what would be helpful.
<b>Other first order categories</b>	
Parent brightening up on seeing participant	005: we ended up taking the train or coach down to x and erm started seeing her twice a year which seemed to brighten her up a lot and she got very excited and happy
Parent wanting contact/reciprocal desire for contact	001: wanting to make contact with his family, things like that. And he reached out to us through the social worker and we made arrangements then to go and see him.  003: he'd send me letters, we'd go and see him.  I remember he used to write me letters and like I said we used to go around visiting him  005: she used to write letters, cards, a lot of it was 'I miss you' over and over again
Parent wanting/initiating contact with participant's sibling(s)	003: she would see him if she was like home and things but I mean he would send her letters and he would always try and get in contact with her but I think, she has made an effort now and again

Not seeing parent for a long time	005: we hadn't seen her for almost like a decade in time
Openness	005 – I'm quite glad ...that my Dad was never someone who wanted to prevent us.... We were always the ones opening it (the letter[s])
Being a tricky time	005: it was a bit of a tricky time to navigate
Parent being proud of participant	004: my mum now as well she's so proud of me and my brother erm and she tells us all the time  005: I remember how happy he was and even though it's a strange relationship because he's not like someone who will say 'I love you' or will give you a hug, it's like you do something that he's really proud of he just says 'good' and nods his head.
Long duration of admission	001: I want to say like 13 years, something like that, I don't know, maybe I'm overestimating that, but it's definitely a long time
Other family (grandparents) worrying about participant's parent	003: My grandparents I can remember them writing a letter, like my grandfather writing letters to the I don't know like head psychiatrist in Wales or whatever... begging them to give him the help  They (grandparents) were afraid he was going to kill himself or kill someone else  I'd see like the heartache that they would go through
Support from teachers/lecturers	004: I remember telling my [music] teacher at the time, I was learning to play and she was sort of my closest like adult that I had that I just told her that I was really that that had happened  005: I got quite a lot of support from one of my lecturers actually
School taking protective action	004: my school got me a little bit of counselling  she'd be late to pick us up from school and school sort of realised and called the authorities
Wanting stability and consistency (as a child)	001: I just wanted to come home and not have to have a drama  you want to come home every day and things to be the same
Wanting a happy family	005: as any two young children at the time wanted, we wanted a happy family, we wanted our parents together

Indirectly impacted by seeing effect on grandparent (primary carer)	003: I do just remember seeing my grandmother upset a lot over the years  My grandmother would have peace of mind like knowing where he was and he was getting the help
Participant's own child a possible motivating factor for parent	003: But now I see like he wants to get better, I don't know if it's because he's got like grandchildren and things now, he seems different this time round
Preparing partner for parent's presentation	003: my partner came as well, and you know I did tell him he might be a bit nervous he's a bit funny with social situations coz he hasn't been in these situations you know
Compare to sibling – noticing differences	005: I compare myself to my sister it seems she doesn't have any of the resentment that I have
Finding out	004: but I remember sort of seeing it [a letter] and taking it and trying to read it and I remember my dad snatched it out of my hand and he burnt it in front of me and I remember I said, I saw it said prison, it said prison, and I can't remember how old I was at this point , I was pretty young, I was probably like 8 or 9, maybe younger. My dad eventually said yes, she's been in prison  005: I can't exactly remember when we found out about my mum trying to stab someone but we were always told from like the age of 13 upwards that there was a mental health issue