Out of sight, out of mind

Ensuring the needs of children of parents with a mental illness are not forgotten in the Mental Health Bill



for children of parents with a mental illness

Executive summary

It is estimated that there are at least 1.6 million children in England living in a household where at least one adult has severe mental health problems [1] - this equates to at least three children per class in every school in the country.

Being a child of a parent with a mental illness is regularly shown to have a significant negative impact on all areas of a child's development. It can also increase the risk of them developing their own mental illness as they grow up. [2]

As the UK's only charity dedicated to supporting children of parents with mental illness, Our Time is concerned that the current draft Bill misses a vital opportunity to significantly improve the identification and support for children of parents subject to detention or community treatment orders under the legislation.

We have proposed a series of tangible recommendations which we believe will help to improve the Bill, by ensuring that children of parents subject to detention or community treatment orders under the legislation are properly recognised and supported:

- Add a duty to 'have regard to' people who care for patients within the Care and Treatment Plan process or introduce a standalone mandatory requirement to ascertain if a patient being detained or subjected to a community treatment order has any children who may need information and/or support.
- Remove the age requirement in relation to being a nominated person.
- Ensure patients have the clear right to choose to involve and disclose confidential information to additional trusted friends and relatives.
- Provide children of parents subject to detention under the Mental Health Act/community treatment orders access to advocacy where needed.

Who is Our Time?

Our Time is the UK's only dedicated charity for children whose parents have a mental illness. We work to give them the support they need - in their families and in their schools. We tackle the stigma around mental illness and show these children they are not alone. We also campaign on behalf of these children to raise the profile of this group, make sure their voices and experiences are heard, and to ensure their needs are reflected in both policy and practice.

With our help, children of parents with mental illness find support and understanding, helping them to build resilience and confidence so they can reach their full potential - this is what every child of a parent with a mental illness deserves.

Children of parents with a mental illness

A significant number of children and young people in the UK are affected by parental mental illness – with the latest figures suggesting around one in three children have a parent with poor mental health [3].

There is currently no data as to the number of children living with a parent who has been detained under the Mental Health Act or who is subject to a Community Treatment Order. But according to analysis from the Office of the Children's Commissioner for England, there are estimated to be at least 1.6 million children in England living in a household where at least one adult has severe mental health problems [4] - this prevalence would equate to there being at least three children in every class in every school. Other reports have found the figures to be even higher.

The House of Lords Public Services Committee report cited that in Manchester 18% of children live in families where one parent has a severe mental health problem [5]. Our Time's vision is for every one of these children to receive the support they need, wherever they live, as early as possible.

Having a parent with a mental illness can negatively impact all aspects of a child's development and is associated with a higher risk of mental illness for the child across the spectrum of diagnosable disorders [6].

This is not just an issue that impacts these children in the short-term. Untreated childhood psychosocial adversity can lead to severe adult health outcomes and has been associated with elevated risk, not just for mental health issues but also physical illness. Children of parents with a mental illness face a 70% chance of developing a preventable mental health issue themselves, with 40% requiring treatment by the age of 20 [7].

Parental mental illness is considered an Adverse Childhood Experience (ACE) and is listed among the 10 leading causes of toxic stress in children [8]. It also frequently lies behind other ACEs, including domestic violence, neglect, substance misuse and homelessness.

Adults who have experienced four or more ACEs are 37.5 times more likely to have attempted suicide than those who have experienced none and are between two and three-fold more likely to develop cancer, heart disease, or respiratory disease [9].

Out of sight, out of mind

Despite the vast number of children and young people affected by having a parent with a severe mental illness, this group of children and young people regularly tell us that they feel forgotten or ignored. Regularly they are not considered within mental health policy, nor is their need for recognition, information, and support. My mum was first sectioned when I was about three or four. There were numerous times when the police had to be involved because she'd run off again and they needed to find her – when the police first came around about mum, I thought that meant she'd done something wrong and was going to get arrested - I remember wondering if I would ever see my mum again.

There were multiple years where my mum would spend more than half of it in hospital because of her mental health, and so much of my routine after-school and weekends was going with dad to visit mum in hospital. Yet no-one from the hospital, none of the psychiatrists involved, ever asked me or my dad if I needed any support. They never gave me the chance to ask the questions I had – I knew mum was getting sectioned – but it took years for me to even know what that meant!

Aaron

The Mental Health Act Code of Practice [10] does reference young carers in relation to:

- Ensuring professionals identify them to 'ensure that health and care services assess those carers' needs and, where relevant, provide support to meet them'. [11]
- Ensuring they have access to 'practical and emotional help and support to assist them in participating' in decision-making. [12] This information should be appropriate to the age and understanding of the young person and professionals need to 'balance the interests of the child against the patient's right to privacy and their wishes and feelings'. [13]
- Always offering 'information which may help them understand the nature of mental disorder generally, the ways it is treated and the operation of the Act'.
 [14]

Despite the above provision in the Code of Practice, there are still trusts who do not regard young carers or children of parents with a mental illness as being relevant to them. Our Time recently wrote to every trust in England inviting them to participate in a webinar examining this particular group of children and young people. A small minority responded positively and signed up and/or promoted the webinar, yet there were some who did not see this as something for them:

C NHS Foundation Trust only provides mental health services for adults aged 18+. Please contact B Mental Health Trust and T Foundation Trust.

Mental Health Trust

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Whilst most mental health trusts have information about support for adults supporting someone with a mental illness and their rights, the same is not the case in relation to support available for children.

Our Time recently reviewed the website of every mental health trust in the country and 59% of trusts had no information about support available for children of parents with mental illness (or young carers). Using a RAG-rating system, only eight trusts received a green rating for having good levels of information available. See Appendix 1 for the summary of our findings across the trusts.

Children of parents with mental illness & the draft Mental Health Bill

Given the wide-ranging areas that the independent review and the draft Bill have covered, at Our Time we are concerned that none of the documents referenced in relation to the draft Bill so far [15] have considered how the legislation and associated statutory guidance is working in relation to children of parents subject to the legislation. Our experience, and that of other members of the <u>Young Carers Alliance</u>, is that children of parents being sectioned or subject to community treatment orders are not being identified by adult mental health professionals. This delays potential young carers being linked into specialist support or referred for a Young Carers Needs Assessment by their local authority under the Children Act 1989. A snapshot survey by the charity Caring Together earlier this year found that, on average, young carers were caring for three years before being linked into support, and for some it was 10 years until they were identified for support. [16]

As the leading charity for children of parents with mental illness, Our Time has identified a number of tangible ways the draft Bill could be improved to ensure we don't miss this key opportunity to improve the experiences of children of parents with a severe mental illness:

Recommendation 1

Add a duty to 'have regard to' people who care for patients within the Care and Treatment Plan process or introduce a standalone requirement to ascertain if a patient subject to the Act has any children who may need information and/or support.

We welcome the inclusion of a duty to consult (if practical and appropriate) anyone who cares for the patient or who is interested in their welfare when preparing or reviewing a care and treatment plan. [17]

Whilst this should in theory include children of patients, we would recommend this is made explicit in revised statutory guidance, if not the legislation itself. There is a concern that children may be deemed impractical to consult with because of potentially not being present in the hospital, due to attending school or college. Our bigger concern is that children will not even be considered because the professionals involved only think of adults who are providing care. We believe that the Care and Treatment Plan process presents an ideal opportunity to take a whole-family approach and ensure that family members (including children) have the information and support that they need. We would recommend adding a requirement to 'have regard to' or 'consider the potential needs for support of' any carers or children of patients to the duty to consult. This would help to ensure that children of parents with a severe mental illness are not left without support and are assessed for their own need for support by their local authority if appropriate.

An alternative approach would be for the legislation to contain a standalone requirement to ascertain if patients being detained or subject to a community treatment order have children, and whether those children need support. This would mirror the approach that has been adopted in recent years in countries such as the Netherlands and Norway.

In the Netherlands, since 2013 it has been a mandatory requirement for every mental health care professional to complete a 'child check'. A child check is when professionals check whether a family of a parent with a psychiatric disorder have children and, if so, whether those children are safe. [18]

In Norway, not only is there a statutory requirement for health professionals to ascertain if patients have minor children, but they are also required to clarify whether the child has the need for information or follow-up support. [19]

The legislation then goes on to stipulate specific tasks the health professional must complete in relation to the child, including:

- Talking to the patient about the child's information or follow-up needs and offering information and guidance on relevant measures. Within the framework of the duty of confidentiality, healthcare personnel must also offer the child and others caring for the child to take part in such a conversation.
- Obtaining consent to carry out follow-up that the healthcare personnel consider appropriate.

• Helping ensure that the child and persons caring for the child, in accordance with the rules on confidentiality, are provided with information about the patient's condition of illness, treatment and the possibility of access. The information is also required to be provided in a form that is adapted to the recipient's individual circumstances.

By adopting a similar approach with the draft Bill, this would significantly increase the likelihood of children of parents with mental illness being identified at an early stage. This in turn would reduce the chance of the child or family reaching crisis point before the need for support is identified.

Recommendation 2

Remove the age requirement in relation to being a nominated person.

We believe that the requirement for a nominated person to be aged 16 or over (in relation to a patient who is 16 or over) fails to acknowledge the essential role that many young people younger than 16 play in the care for their parent. This is particularly the case in lone-parent households where the young person may be the primary source of support/carer.

They never talk to me or ask me for my opinion – even though I'm the one who has to support mum all of the rest of the time. I just want them to listen to me and to tell me who I can talk to if I am worried about her.

Fran

Whilst we completely support the need to ensure that children are not subject to excessive or inappropriate responsibilities and acknowledge the link between the proposed age and the age under the Mental Capacity Act 2005, this approach is not

in line with the approach recently taken with the Health and Care Act 2022. In that legislation, there is no age requirement in relation to the duty on hospital trusts to consult with carers prior to discharging an adult patient who is likely to need care and support following discharge. [20]

In addition, we feel that the age requirement for a nominated person is not necessary because the witness (health and care professional or independent mental health advocate) is required to make a statement that they have 'no reason to think that the nominated person lacks capacity or competence to act as a nominated person'. [21] This clause would ensure that a child is not appointed to the role where there are concerns as to their capacity or competence to take on the role.

In relation to competency, we would welcome the inclusion of clear guidance as to ascertaining competency of a prospective nominated person in any revised statutory guidance for the legislation. We feel that this is important so as to ensure consistency when determining if an individual should be a nominated person. This guidance should include how this relates to children who a patient may want to choose as a nominated person.

Recommendation 3

Ensure patients have the right to choose to involve and disclose confidential information to additional trusted friends and relatives.

An alternative approach to the above recommendation would be to ensure that parents could choose to involve their children and enable them to receive appropriate information about their parent's care.

We fully support the recommendation of the Independent Review that patients should have greater rights to involve and disclose confidential information to additional named individuals outside of the nominated person process. This would be beneficial to patients and their families where the primary carer (or nominated person) may also be working, and so this would enable other trusted friends and family members to be involved. This could include a child of the parent. This would also help ensure that the role of children of parents with a mental illness can be recognised, even if it is felt not appropriate to remove the age requirement in relation to the nominated person role because of the level of responsibility attached to the role.

Recommendation 4

Provide children of parents subject to detention under the Mental Health Act/community treatment orders access to advocacy where needed.

From our years of supporting children of parents with mental illness, we often hear from them how complex and confusing the mental health system can be, particularly when someone is being detained under the Mental Health Act. For children and young people, it is often difficult to know who they should speak to, and they may not always have the confidence to challenge proposals or decisions being made in relation to the care of their parent.

Under the current draft Bill, young people aged 16 and over can be appointed as a nominated person, but there is no support for these children/young people available if required to help ensure their voices can be heard.

One way of improving the draft Bill in relation to children of parents subject to the Act would be to provide them with the right to advocacy under the Act where it's deemed appropriate. Particularly if they are undertaking the role of the nominated person.

What difference would better information and support for children of parents with mental illness make?

From our years of supporting hundreds of children of parents with mental illness and their family, and by speaking directly to children/former children themselves, we know that improving the identification, recognition, information and support available for children of parents detained under the Act could make a huge difference to their own health and wellbeing and help them feel more able to cope.

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If I'd have been given information when my mum was in hospital, it would've helped me understand what was happening to her and reassure me that she would get better (if not forever, but for significant periods of time). It would have put my mind at ease as to what the hospital was doing to help her, like they do when someone has a physical illness. Somebody explains that to you and tells you how they'll help. With mental illness, it wasn't the same. I just saw my mum as a shell of who she was, sedated on medication, with little understanding of how she was being helped.

First and foremost, the information about what was happening would have reassured me in knowing my mum was being well looked after. It also would have helped me have the words to explain to others, rather than keeping it a secret. It might have helped me to see through the stigma that surrounded mental health and feel less worried about upsetting my mum by talking about things. I also felt huge empathy for others, and I hated the thought of her feeling guilty, so would bury my fears. I know that being offered support would have been difficult to accept as I came from a loving and solid family home; so I would've felt that others needed the help more. But I also know it would've made the world of difference to me. Having the opportunity to talk to someone who understood and listened without judgement would've helped me process what was happening in a safe space. I feel like I could've found techniques to help myself cope with the worry, as well as tips as to how I might be able to help my mum. Not long after my mum was first hospitalised, I started controlling my food intake and struggled with normal eating for around eight years. I don't blame my mum's illness at all, but I think if I could have found better coping mechanisms, I may not have struggled in this way.

Suzie



As a highly sensitive, intuitive child and young person, I would have appreciated having my experience validated first and foremost. I intuitively sensed that things were not good, and that we were in crisis as a family, but rather than someone validate that, let me express my emotions and coregulate with me, everyone pretended everything was fine. My sister and I would be taken to stay with friends' parents, and everyone seemed to pretend nothing was happening.

Having someone to speak honestly without treading on eggshells would have been so comforting. When my dad was sectioned and admitted into care, I totally appreciate that must have been an incredibly challenging time for my mum. Perhaps if the support was available to my mum at the time, she would have had support to communicate the situation with my sister and me. I truly believe I learned to push my emotions down for fear of upsetting people and started distrusting my intuition because of these experiences.

Jess

Appendix 1

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A RAG-rating of Mental Health Trust's information on their website around young carers and the support available completed in August 2022.

No information found Limited information G

Good levels of information

Trust	Information
1	Good information including top tips; they have a dedicated leaflet
2	No information about carer support
3	No mention about young carers or their rights under Children Act 1989
4	Very little mention – it does signpost to local Young Carers service
5	Limited reference to young carers
6	No visible mention of carers
7	No mention of young carers
8	Lots of information including films, organisations who can support
9	Good information including leaflets for professionals/young people
10	No local information for young carers and only visible when you get to 'Support for carers' page
11	No mention of young carers

12	No mention of young carers
13	No mention of young carers
14	Has limited resources including young carers – you have to search for them to find in resource library; they have a young carers leaflet and video
15	No mention of young carers
16	No mention of young carers (other than in their carers' strategy which expired 2021)
17	Mentions young carers once but no information about support
18	No mention of young carers
19	No mention of support for young carers
20	Included but not referenced in description of who they might be supporting
21	Mentions young carers; has booklet about visiting a secure hospital for children and young people, but limited mention about support
22	Limited information - mentions Care Act but not Children Act 1989. Specific young carers mental health information leaflet in carers' resources section
23	No mention of young carers
24	No mention of young carers
25	No mention of young carers

26	No mention of young carers
27	Very little mention - mentions Care Act assessments but not Children Act 1989
28	No mention of young carers
29	Does mention young carers and links to young carer service; last newsletter was April 2021
30	No mention of young carers (except in their carers charter)
31	No mention of young carers
32	Specific section on young carers with lots of links to support (doesn't explain who a young carer is)
33	No visible mention of carers
34	Really out-dated information; no mention about support for young carers
35	No mention of young carers
36	No mention of young carers
37	No mention of young carers
38	Young carers section with tips on who to speak to and local links to support (doesn't mention that they might be providing emotional support)
39	No mention of young carers
40	No mention of young carers other than links to the local support providers

41	No mention of young carers (other than in a news story)
42	Lots of information about young carers and co-produced resources including guide to support
43	No mention of young carers
44	No mention of young carers
45	No mention of young carers
46	There is a young carers page, but the link is very easy to miss and much of the information is out of date
47	Very limited mention of young carers
48	Mentions young carers but no clear information on support available
49	Young carers section with links to support (had to search to find it)
50	Does have a young carers link but takes to national NHS page; links to young carer support within wider support page
51	No mention of young carers
52	Does have a young carers link but doesn't say who young carers are and takes to national NHS page
53	No mention of young carers
54	Includes links to young carer organisations but no explanation of who a young carer is

End notes

- 1 Estimating the prevalence of the toxic trio evidence from the adult psychiatric morbidity survey, Office of the Children's Commissioner, 2018
- 2 Nelson et al (2020) Adversity in childhood is linked to mental and physical health throughout life. Bmj, 371
- 3 Children living with parents in emotional distress: March 2021 update, Public Health England
- 4 Estimating the prevalence of the toxic trio evidence from the adult psychiatric morbidity survey, Office of the Children's Commissioner, 2018
- 5 House of Lords, Public Services Committee (2020) A critical juncture for public services: lessons from COVID-19, para,59 available at <u>A critical</u> juncture for public services: lessons from COVID-19 (parliament.uk)
- 6 Nelson et al (2020) Adversity in childhood is linked to mental and physical health throughout life. Bmj, 371
- Campbell et al (2020) Prevalence of mental illness among parents of children receiving treatment within child and adolescent mental health services (CAMHS): a scoping review. Eur Child Adolesc Psychiatry, pp.1-16
- 8 Our Time (2020) Evidence review: <u>Children of parents with a mental illness</u> <u>during the COVID-19 pandemic</u>.
- 9 Nelson et al (2020) Adversity in childhood is linked to mental and physical health throughout life. Bmj, 371

- 10 Available at Mental Health Act 1983 (publishing.service.gov.uk)
- 11 Paragraph 4.42
- 12 Paragraphs 4.44
- 13 Paragraph 4.47
- 14 Paragraph 10.13
- 'Modernising the Mental Health Act Increasing choice, reducing compulsion' Final report of the Independent Review of the Mental Health Act 1983; December 2018, 'Reforming the Mental Health Act: Government response to consultation', July 2021, 'Reforming the Mental Health Act' Research Briefing; July 2022
- 16 <u>From-caring-to-support-we-still-need-to-close-the-gap-for-young-carers-</u> <u>PDF-158kB.pdf (caringtogether.org)</u>
- 17 (s18(6))
- Domestic violence and child abuse protocol | Domestic violence |

 Government.nl
- 19 S10(A) Health Personnel Act
- 20 Section 91
- 21 (Schedule 2, Part 1 (3)(2)(c)(iii)

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