Promoting resilience in children and adolescents living with parental mental illness (CAPRI): children are key to identifying solutions

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Summary
The lives of Children and Adolescents with PaRental mental illness (CAPRI) represent a public health priority. Identifying those at most risk within the risk subset is crucial to promote resilience for this group. The ability to develop child-centred interventions will underpin the success of evidence-based services and CAPRI themselves are key to unlocking current service barriers.

Declaration interest
None.

Evidence of need
Our previous population-based research details significant premature mortality from all causes up to the age of 30 years among CAPRI, especially where maternal admission for substance misuse occurred. The reality is that mortality is too rare an outcome to drive new policy and services but little information is available about more common, tractable outcomes like physical health, social/criminal justice or cognitive ability, let alone quality of life and well-being. Most research focuses on mothers, ignoring the father’s role in the child-rearing environment and most does not account for the multiple adversities CAPRI experience growing up with parental mental illness. We do know that these young people experience significant disruption to their lives from repeated parental admission to hospital and illness. The available evidence indicates that the lack of usual parental supports and disruption of family life impacts educational, social and emotional attainment and is associated with behavioural difficulties.

Information fit for purpose
Although a range of national policies now identifies CAPRI as a priority, there is a clear, urgent need for better information so that policymakers can allocate resources early and intelligently towards those most at risk. Specifically, we require information on the effect of parental mental illness at different times in a child’s life.
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Sciences that current administration of data governance is not fit coordinated to allow better quality research with the appropriate Administrative, health survey, clinical and cohort data need to be remain unavailable for linkage within whole population data-sets. collected to a high standard in clinical or health survey data so personal violence and/or school bullying. These data are not routinely at, for example, primary care or school entrance. In our view, this challenge and unblock information governance restrictions, meaning for purpose. CAPRI themselves could be a powerful lobby to chal-

enge and unblock information governance restrictions, meaning better or more routinely collected mental health and social data at, for example, primary care or school entrance. In our view, this is crucial if we are to find reliable potential markers of resilience/ risk at the earliest opportunity.

Identifying need

Child and Adolescent Mental Health in Europe calls for better information and evidence to provide adequate services and interventions for children with parental mental illness. In our view, young people should be at the heart of decision-making about service development and the prioritisation of their (primarily non-clinical) needs. Most children with parental mental illness are not receiving any services; if resources flow to the wider family, they do so through the ill parent who may have a social worker and multidisciplinary mental health team. Our work suggests CAPRI themselves want and need basic day-to-day supports, rather than specific interventions for an illness. However, barriers to sharing information between adult mental health and other agencies means early identification of CAPRI need remains challenging. This is a missed opportunity: CAPRI could be readily identifiable through their parents’ contact with psychiatric services as well as through schools and primary care. The NHS and PHE could play a key role by engaging with CAPRI and other stakeholders to challenge services to work together and improve routine, non-stigmatised identification of their needs. Standardising communication and information sharing across schools, mental health services and social services supports the remit of a reinvigorated mental health service data-set which might offer solutions to the curation of CAPRI data across settings.

Identifying risk

Although this group faces adversity many demonstrate resilience, so a major challenge is to identify what fosters resilience in some and what places others at highest risk. Asking young people what helps them day to day must be at the heart of our understanding. Clinical risk modelling applied to this group must be informed by CAPRI for better understanding of how resilience and risk maps onto particul-

ar life outcomes. In cardiovascular medicine, such algorithms suc-

cessfully identify resilience and risk to enact preventative interventions. We believe such techniques can be exploited in non-clinical samples of CAPRI. Furthermore, the focus of public mental health should not be limited to service-linked outcomes; little is known about the quality of life for the majority of CAPRI who do not come to the attention of services and who may wish to remain outside traditional service models. Consultation and co-development of outcomes with CAPRI is vital for success.

Service landscape for CAPRI

Globally, only Australia has a well-recognised policy and service platform dedicated to CAPRI. Most countries remain unaware of them and their support needs. Part of the problem is that, once children are identified, lack of information about modifiable factors driving CAPRI outcomes means few dedicated, evidenced, child-centred or cost-effective programmes exist. Recent reviews found contemporary interventions were all parent/family centred and small effect sizes, costly training and time commitments restrict delivery. Most interventions explicitly aim to reduce risk of later psychopathology and fail to consider other child-centred outcomes. Developing an evidence base for cost-effective interventions requires targeting the highest risk children within families and this means having better predictors of resilience and risk over time. It also means identifying young people’s own outcome priorities. Initiatives that facilitate CAPRI as citizen researchers are vital to achieve this and they have encouraged young people to co-develop research priorities and child-centred interventions which are both acceptable to them and feasible to deliver within the current UK service contexts.

Future research

At the University of Manchester, we have adopted an interdisciplinary approach to this broad problem with a children and young people’s advisory group at its heart. These citizen researchers help us formulate questions in four domains. First, we are creating parallel population data-sets held in Sweden, the UK and Australia to determine preva-

lence of CAPRI. Second, we are tracking broad, non-psychopathologi-

cal outcomes (informed by CAPRI) across the life course. This provides the valuable population evidence currently unavailable and allows for the timely identification of CAPRI at highest risk for preventative interventions for more common adverse outcomes. Advisory group members will prioritise and modify how we frame questions about what social adversity and resilience means. Third, we shall map the risk model (informed by our CAPRI advisory group and the epidemiology) onto a clinical cohort of 9- to 18-month-old infants with severe maternal mental illness to stratify them into ‘higher’ and ‘lower’ risk. We shall then test the validity of our risk modelling using functional near infrared spectroscopy (fNIRS). fNIRS can assess the cortical development of speech and lan-

guage acquisition in at-risk infants from 6 months. We hypothesise that the ‘highest risk’ stratified sample will show significant differences in cortical language processing compared with those in the ‘lower risk’ strata and compared with infants of well mothers. Such early ‘biomarkers’ may allow future routine clinical identification of those at highest risk within this population of vulnerable children and young people, providing valuable evidence for the development of targeted and timely interventions to improve outcome and quality of life. The fourth element of work is a pathway of child-centred supports including digital and face-to-face aspects co-developed by young people.

Conclusion

Recent focus on the well-being of children and young people presents a unique opportunity for CAPRI – an easily identifiable, often resili-

ent, but highly vulnerable group. There is a clear need for new ways of
thinking about this important but hidden public health problem, including addressing current concerns about data access for the sake of public benefit. Placing CAPRI at the centre of decision-making is essential if future policy, research and service development is to improve their lives in a sustainable manner.

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