

Improving the mental health of children and young people with long term conditions

What does the evidence tell us?

Briefing Paper

March 2019

Many children and young people with a long term physical condition also experience feelings of depression, anxiety and other mental health issues and this impacts on their day to day life, their family and others around them. The overall risk of diagnosed mental health difficulties is reportedly around four times greater in children and young people with long term conditions than in their physically healthy peers.

This is a summary of a systematic review that used robust methods to identify, appraise and bring together all the available information on the treatment of mental health in children and young people with long-term conditions.

- ◆ We included information about whether interventions (treatments, strategies and resources) can help children and young people with their mental health. Much of the information came from studies that were small and not very well designed or carried out.
- ◆ There is some evidence for positive effects on both mental health and other outcomes for cognitive behavioural therapy.
- ◆ We also included studies that explored the attitudes and experiences of those involved in receiving or delivering interventions. These studies were often conducted well, but they focused on different interventions than those evaluating how well interventions work.
- ◆ Building good relationships and delivering interventions in what feels like a safe space were perceived to be important elements of successful interventions.
- ◆ Participants in studies tended to like interventions that provided social support and helped them feel better about living with a long term condition.
- ◆ Successful interventions were seen as accessible and engaging.
- ◆ There are many gaps where interventions have not been studied for specific long term physical conditions. Although we included studies of interventions aiming to improve mental health, the majority also targeted other outcomes, particularly LTC symptoms. Therefore future research might consider integrated treatment and its effects across broad health outcomes.

'Children and young people with long-term health conditions – be it cancer, brain injury, muscular dystrophy or any of a myriad of physical conditions that can't be cured, only managed – face enormous challenges. As well as their physical illness, many of these young people suffer from mental health problems as a consequence of their condition.'

*Fiona Lockhart, parent
and co-investigator*



**Please use this QR
code to navigate to
the project website**

Why did we do it?

Despite advances in medicine leading to improved prognosis and/or cures for many conditions, long term conditions continue to be common in children and young people. There is extensive evidence that links the presence of a long term condition with increased risk of the development of a mental health diagnosis.

The closer integration of mental and physical healthcare is a priority for the NHS¹ and the NHS Confederation has highlighted the social, health and economic benefits that arise from integration of physical and mental health treatments². However, at present we do not know what 'best practice' consists of in relation to the treatment of mental ill health in children and young people with long term

conditions.

A wide range of factors may influence the effectiveness of mental health interventions for children and young people e.g. the developmental stage of the child, family circumstances, accessibility of interventions, relying on others to access treatment, attentional requirements, keeping children engaged and interested and the need to work around education.

Our aim in this project was therefore to evaluate the effectiveness of interventions aimed at improving the mental health of children and young people with long term conditions and to explore the factors that may enhance or limit their delivery.

"This report contributes to the growing emphasis and ambition within clinical services to integrate physical and mental health care for children. The well-being and mental health needs of children with chronic illness have been identified as a priority in the NHS 10 year plan, and these findings support the national drive to detect and treat these difficulties."

Dr Isobel Heyman, Lead Psychiatrist at Great Ormond Street Hospital for Children and a collaborator on the project



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How did we do it?

Finding the literature: We searched 13 bibliographic databases, the references of included sources, relevant reviews and websites.

Eligibility criteria: We included randomised controlled trials or economic evaluations involving children and young people aged 0-25 years with long term conditions and elevated symptoms of mental ill health. There was no restriction on the type of intervention. Effectiveness had to be measured in terms of impact on at least one measure of mental health. We also included primary qualitative studies that explored attitudes and experiences of interventions from the perspectives of the young

people, their families and/or practitioners.

Study selection, data extraction, study quality and synthesis: In line with best practice, all stages were completed independently by two reviewers. Studies of the effects of interventions and the attitudes and experiences of interventions were first brought together separately using established methods of synthesis. We then integrated the findings from these reviews in an overarching synthesis.

End user involvement: We integrated end-user involvement throughout the project in the form of input and feedback from topic experts, children and young people and their parents, as well as consultation on preliminary findings with a range of interested parties.

Where was the evidence from?

25 randomised controlled trials met our inclusion criteria for the assessment of the effectiveness of interventions. These studies evaluated 11 types of intervention, sampling children and young people with 12 different types of long term conditions.

We found a further 57 studies, evaluating the attitudes and experiences of 21 types of intervention representing views from a range of different participants involved in the delivery and receipt of relevant interventions.

Can interventions (treatments, strategies and resources) help children and young people with their mental health?

- * Of the 11 reported interventions, the greatest volume of research focussed on the effectiveness of cognitive behavioural therapy (CBT), with seven studies evaluating this type of intervention.
- * These studies provide tentative evidence that CBT-based interventions could be beneficial for the mental health of children and young people with inflammatory bowel disease, chronic pain, epilepsy and persistent functional somatic complaints, but not type 1 diabetes mellitus.
- * Some of the effective CBT interventions featured content which was adapted to the specific long term condition prior to intervention delivery.
- * Four parenting programme interventions were evaluated in three studies. Group play therapy interventions were also assessed in three studies. Other intervention types were seen in only one or two studies. Trials were typically small, meaning effect sizes across the included studies were characterised by wide confidence intervals. The evidence for these interventions used with similar samples of children and young people is therefore very limited.
- * None of the studies were conducted in the UK.

What do we know about the attitudes and experiences of those involved in receiving or delivering similar interventions?

- * Included studies commonly explored the perceptions and experiences of interventions aimed at improving coping, self-esteem and emotional support rather than targeting symptoms directly related to a mental health disorders such as depression or anxiety. Interventions often aimed to improve symptoms related to the long term condition and social skills as well as mental health.
- * Having a safe space where they could talk about how they were feeling and escape the routine and stigma associated with having a long term condition were themes commonly reported by participants in relation to interventions they felt were effective.
- * We developed a explanatory model that describes the process by which children and young people with long term conditions access and maintain engagement with a relevant mental health intervention and is based on five main constructs - A 'Therapeutic Foundation', 'Social Support', 'A Hopeful Alternative', 'Resilience' and 'Getting In and Staying In'.
- * Participants reported that some interventions helped children and young people to acquire a sense of hope for the future and increase their resilience.
- * Participants valued the opportunity to meet other peers with a long term condition using it as an opportunity to learn new information about living with their physical and mental health difficulties.
- * There is some evidence that interventions responding to the needs of individuals, particularly in relation to their long term conditions, may be beneficial.
- * Interventions that include family, particularly parents, may be beneficial.
- * There appear to be more benefits than disadvantages when children and young people are able to meet peers with similar health needs as part of an intervention.
- * There is an indication that relationships between children and young people with long term conditions and their therapists and peers are important.
- * An intervention's setting, use of technology and flexibility may impact perceived effectiveness.

What have we learnt?

Given the nature of the review findings recommendations for policy and practice are tentative.

Implications for policy and practice

- ◆ There is evidence that CBT may be beneficial for children and young people with some long term conditions e.g. epilepsy, persistent somatic functional complaints, inflammatory bowel disease and chronic pain.
- ◆ There is some evidence of the effectiveness of parenting programme interventions to reduce behavioural problems in children with acquired brain injury and/or cerebral palsy, particularly when combined with acceptance and commitment therapy.
- ◆ Children and young people value interventions that consider a range of needs as opposed to focussing solely on their mental health. Therefore, consideration of collaborative approaches between different treatment providers and educators may be of benefit.
- ◆ Integration of opportunities to build supportive relationships with peers and meet people who are successfully managing their long term condition may be useful for some children and young people.

Implications for future research

- ◆ Overall, the evidence on whether interventions can help children and young people with their mental health highlights the need for a) further, rigorous testing and reporting of manualised interventions (treatments that are defined and delivered according to a detailed manual) and b) consensus on the use of outcome measures.
- ◆ Priority areas for research include:
 - ◆ Mixed methods process evaluations to explore why some interventions may (or may not) be effective and to identify the moderators of effectiveness,
 - ◆ Exploring the benefits of adapting intervention content to specific long term conditions and being flexible to the changing developmental and physical needs of the patient,
 - ◆ Investigating methods to create services where physical and mental health needs are managed in a genuinely integrated way,
 - ◆ Considering ways in which technology could improve intervention delivery.

'I think researchers need to develop effective methods of improving mental health, and these need to be implemented in schools, as well as outside. Tackling mental health problems before they become too overwhelming, would be beneficial to the young person's physical health, and life in general.' Member of Children & Young People's Advisory Group

The project was conducted by Darren A Moore, Michael Nunns, Liz Shaw, Morwenna Rogers, Tamsin Ford, Rob Anderson, Chris Dickens, Ruth Garside, Obi Ukoumunne, Stuart Logan and Jo Thompson Coon from the University of Exeter, Erin Walker, Isobel Heyman and Penny Titman from Great Ormond Street Hospital for Children NHS Foundation Trust, Roz Shafran and Russell Viner from University College London and Fiona Lockhart from the Biomedical Research Centre Patient & Public Involvement Group at University College London Hospitals. Our dedicated Children and Young People's Advisory Group and their parents contributed to all stages of the project.

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The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

More information including a link to the full report, blog posts, podcasts and conference presentations can be found on the [project webpage](#).

1. Department of Health. *No Health Without Mental Health: A cross-government outcomes strategy*. London: Department of Health; 2011.

2. NHS Confederation. *Investing in emotional and psychological wellbeing for patients with long-term conditions*. London: The NHS Confederation; 2012.