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A scoping literature review of service-level barriers for access and engagement with mental health services for children and young people

Joanna K. Anderson[a,*], Emma Howarth[a], Maris Vainre[a], Peter B. Jones[b], Ayla Humphrey[a,c]

[a] NIHR CLAHRC East of England, University of Cambridge, Institute of Public Health, Douglas House, 18 Trumpington Road, Cambridge CB2 8AH, United Kingdom
[b] University of Cambridge, Department of Psychiatry, Herschel Smith Building, Forvie Site, Robinson Way, Cambridge CB2 0SZ, United Kingdom
[c] Cambridgeshire and Peterborough NHS Foundation Trust, 18 Trumpington Road, Cambridge CB2 8AH, United Kingdom

1. Introduction

The worldwide-pooled prevalence of mental disorders in children and adolescents is estimated at 13.4% (Polanczyk, Salum, Sugaya, Caye, & Rohde, 2015). In the UK one in ten children aged 5–16 years suffer from a diagnosable mental health (MH) condition while many more are experiencing symptoms that, while not reaching the threshold of clinical disorder, are a source of distress for children, young people and their families (Green et al., 2005). Only 25% of children with clinically significant MH problems receive specialist care (Hagell, Coleman, & Brooks, 2015), while 43% report no MH related service contact at all (Ford et al., 2005). MH problems in childhood, unless treated, have a high level of persistence (Meltzer et al., 2003), with some conditions persevering through adolescence and into adulthood (Woodward & Fergusson, 2001). It is estimated that 25% of children with emotional disorders and 43% with conduct disorder still have the same condition three years later (Meltzer et al., 2003). A half of lifetime mental illnesses start by the age of 15 and 74% by the age of 18, increasing still further among those who use specialist mental health services by their mid-20's (Kim-Cohen et al., 2003). Failure to address MH problems early in life not only affects individuals' long-term functioning and wellbeing, but also produces significant societal costs resulting from increased healthcare usage, unemployment and anti-social behaviours (Joint Commissioning Panel for Mental Health, 2013). Snell et al. estimated yearly additional health, social care and educational costs associated with children psychiatric disorders in the UK at around £1.47bn (Snell et al., 2013).

Ample evidence suggest that service-level barriers are only one of the key factors hampering timely connection of children and young people experiencing MH difficulties with appropriate supportive services (Brown et al., 2015; Gondek et al., 2016; Gulliver, Griffiths, & Christensen, 2010; Reardon et al., 2016; Rowe et al., 2014). Service-level barriers for access and engagement have been highlighted by different groups of service users, including the most vulnerable ones, as well as providers, and commissioners. A recent systematic review of barriers encountered by young people seeking MH support identified lack of knowledge about available services, difficult access and stress associated with help-seeking process among key barriers to accessing MH services (Gulliver et al., 2010). Brown et al. (2015) systematically reviewed studies of barriers for access to MH support encountered by young people from at-risk groups including ethnic and sexual minorities, culturally and linguistically diverse, homeless, substance users and youth residing in remote and rural areas. Apart from barriers specific to particular at-risk groups (e.g. language barrier, cultural norms, fear of being shamed), key barriers included lack of awareness of available services, system and access restrictions, long waiting times, and inflexibility of services (Brown et al., 2015). A systematic review by Reardon et al. (2016) focusing on parents' perception of barriers for access and engagement with services for children and adolescent experiencing MH difficulties identified structural and systemic issues, and complicated help seeking process among key factors hampering timely access to services. A systematic review by Gondek et al. (2016) named limited resources, lack of information about available services, extensive and inflexible policies and regulations, and inflexible treatment provision major barriers for delivery of person-centred care in child and young people MH services. A systematic review focusing on barriers encountered by primary care practitioners managing children and adolescents MH problems (O'Brien, Harvey, Howse, Reardon, & Creswell, 2016) identified extensive waiting lists, financial restrictions and insufficient resources as key factors hampering their efforts to provide MH support in primary care settings.

In accordance with research evidence, the UK Department of Health recognised timely access to services and treatment as a major barrier for achieving parity of esteem for MH (Department of Health, 2011; Department of Health, 2014a). Improving access to care is a key principles underpinning the ongoing redesign of Children and Adolescent Mental Health Services (CAMHS) (Department of Health, 2015); by 2020 the UK government aims to have developed a comprehensive set of access and waiting times standards on a par with those seen in physical health service (Department of Health, 2014b; Department of Health, 2015). The recent report, Children and Young People's Mental

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* Corresponding author.
E-mail addresses: joanna.anderson@medschl.cam.ac.uk (J.K. Anderson), emma.howarth@medschl.cam.ac.uk (E. Howarth), maris.vainre@medschl.cam.ac.uk (M. Vainre), pbj21@cam.ac.uk (P.B. Jones), ayla.humphrey@cpft.nhs.uk (A. Humphrey).

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Health Taskforce "Future in Mind" outlines key principles of CAMHS improvements (Department of Health, 2015) including improving timely access to services. Further guidance sets out strategies to operationalise these principles over the next five years through local level improvement initiatives guided by Local Transformation Plans (NHS England, 2015). These plans are developed by local Clinical Commissioning Groups, working closely with Health and Wellbeing Board Partners, and with strong input from children, young people and those who care for them (NHS England, 2015).

In 2015 CLAHRC East of England conducted a consensus study with service users and the children and young people's workforce to identify priorities for the delivery of community based CAMHS in the region and to inform the development of Local Transformation Plans. One of the key themes that emerged was the need to enhance access to services and support. In order to translate key priorities into action plans leading to successful transformation of CAMHS, the process needs to be informed and guided by evidence. Although there are a number of recently published literature reviews focusing on barriers to access encountered by various user groups (Brown et al., 2015; Gondek et al., 2016; Gulliver et al., 2010; Reardon et al., 2016; Rowe et al., 2014), commissioners, policy makers and service managers often lack resources to analyse and synthesise a large body of evidence themselves. As a result they are not always able to interpret recommendations and community opinions within a scientifically informed context, risking implementing them in ways which do not optimise access and may erode efficacy (Clarke et al., 2013; Wye et al., 2015). In order to provide decision makers with a readily accessible evidence-base to guide local CAMHS transformation, a scoping literature review was undertaken to identify and aggregate evidence relating to key service development priorities highlighted in the consensus study. This paper reports results of a scoping literature review of barriers children, young people and families encounter when accessing and engaging with CAMHS, and effective strategies to overcome them.

2. Materials and methods

One of purposes for conducting a scoping review is to synthesise and disseminate research results to audiences that otherwise would not have time or resources to conduct a review themselves (Arksey & O'Malley, 2005). A scoping review is designed to provide an overview of literature on a particular topic and to highlight potential research gaps. It provides quantitative summary and qualitative thematic analysis of findings, and discusses implications for research and practice (Levac, Colquhoun, & O'Brien, 2010), however is not meant to be exhaustive, and does not assess the quality of evidence (Arksey & O'Malley, 2005; Levac et al., 2010).

The review described in this paper was guided by a methodological framework for conducting scoping studies proposed by Arksey and O′Malley (Arksey & O'Malley, 2005), and further advanced by Levac et al. (Levac et al., 2010). The final search strategy (See Table 1) was determined after the initial data charting searches (Joanna Briggs Institute, 2015) and consultations with a subject librarian, and included the following: i) searching electronic bibliographic databases: MEDLINE, CINAHL, PsycINFO and Web of Science; ii) hand searching of relevant journals for potentially relevant studies and literature reviews; iii) forward citation search of the reference lists of primary studies included in the review, and the reference lists of relevant, previously published reviews. A three stage screening process, conducted independently by two researchers, included screening titles and abstracts to remove obviously irrelevant publications followed by screening abstracts of remaining publications, and finally full texts of potentially relevant papers for compliance with inclusion/exclusion criteria.

2.1. Inclusion/exclusion criteria

Due to time restrictions and lack of resources for translation services, only publications written in English were included. Since healthcare systems have changed significantly over the last two decades, and it was unlikely that currently delivered MH services were developed based on evidence or policy documents published more than 25 years ago, we included papers published after 1990. We excluded papers that are not empirical or evidence-based, however we included papers synthesising and discussing results of existing studies, or providing an overview of relevant policies and initiatives designed to improve access to services (discussion papers). The World Health Organization (2005), *Mental Health Atlas*, indicates that although the majority of global burden of mental health disorders is in low to middle income countries, 90% of global mental health resources are located in high-income countries (World Health Organization, 2005). Furthermore, only 6% of the research on mental health have been published in indexed journals from these countries (Saxena, Paraje, Sharan, Karam, & Sadana, 2006). The mental health care and the research of this care in low income countries is demonstrably different to that in developed countries and for this reason we only included studies conducted in countries classified as developed economies or economies in transition (United Nations, 2017) (Table 2).

2.2. Data extraction and reporting

Data from included full texts were extracted into tables. A list of key themes was developed and publications were grouped in accordance with the main theme represented in each paper. As recommended by Levac et al. (2010) both a numerical summary of existing evidence and narrative description of findings in relation to the research questions was provided. To summarize available evidence, draw conclusions and make recommendations narrative synthesis of evidence using the framework proposed by Popay et al. (2006) was carried out.

3. Findings

3.1. Descriptive numerical summary

Our searches identified 3177 papers on service-level barriers for access to CAMHS and treatment engagement, and 47 papers were

Table 1
Search strategy.

Barriers for access and engagement with CAMHS	Improving access and engagement with CAMHS
AB ((mental health N2 care) OR (mental N2 healthcare) OR (mental health N2 service*) OR (CAMHS) OR TI ((mental health N2 care) OR (mental N2 healthcare) OR (mental health N2 service*) OR (CAMHS) AND AB (child* OR adolescen* OR teen* OR young people OR young person* OR minor* OR youth* OR infan*) OR TI (child* OR adolescen* OR teen* OR young people OR young person* OR minor* OR youth* OR infan*) AND AB ((barrier* OR problem* OR delay*) N3 (access* OR referr* OR engage* OR utili*)) OR TI ((barrier* OR problem* OR delay*) N3 (access* OR referr* OR engage* OR utili*))	AB ((mental health N2 care) OR (mental N2 healthcare) OR (mental health N2 service*) OR (CAMHS) OR TI ((mental health N2 care) OR (mental N2 healthcare) OR (mental health N2 service*) OR (CAMHS) AND AB (child* OR adolescen* OR teen* OR young people OR young person* OR minor* OR youth* OR infan*) OR TI (child* OR adolescen* OR teen* OR young people OR young person* OR minor* OR youth* OR infan*) AND AB ((wait* N3 (time* OR list)) OR (access time*)) OR TI ((wait* N3 (time* OR list)) OR (access time*)) AND AB (((improv* OR enhanc*) N3 (access* OR refer* OR engag*))) OR TI (((improv* OR enhanc*) N3 (access* OR refer* OR engag*)))