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

Joanna K. Anderson[i] **(corresponding author)**
Email: joanna.anderson@medschl.cam.ac.uk
Emma Howarth
Email: emma.howarth@medschl.cam.ac.uk
Maris Vainre
Email: maris.vainre@medschl.cam.ac.uk
Peter B. Jones
Email: pbj21@cam.ac.uk
Ayla Humphrey
Email: ayla.humphrey@cpft.nhs.uk

1. *Introduction*

The worldwide-pooled prevalence of mental disorders in children and adolescents is estimated at 13.4% [1]. 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, whilst not reaching the threshold of clinical disorder, are a source of distress for children, young people and their families [2]. Only 25% of children with clinically significant MH problems receive specialist care [3], while 43% report no MH related service contact at all [4]. MH problems in childhood, unless treated, have a high level of persistence [5], with some conditions persevering through adolescence and into adulthood [6]. It is estimated that 25% of children with emotional disorders and 43% with conduct disorder still have the same condition three years later [5]. 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 [7]. 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 antisocial behaviours [8]. Snell et al. estimated yearly additional health, social care and educational costs associated with children psychiatric disorders in the UK at around £1.47bn [9].

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 [10-14]. 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 [12]. Brown et al [10] 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 [10]. A systematic review by Reardon et al [13] 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 [11] 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 [15] 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 [16, 17]. Improving access to care is a key principles underpinning the ongoing redesign of Children and Adolescent Mental Health Services (CAMHS) [18]; 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 [18, 19]. The recent report, Children and Young People's Mental Health Taskforce "Future in Mind" outlines key principles of CAMHS improvements [18] 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 [20]. 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 [20].

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 [10-14], 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 [21, 22]. 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 [23]. 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 [24], however is not meant to be exhaustive, and does not assess the quality of evidence [23, 24].

The review described in this paper was guided by a methodological framework for conducting scoping studies proposed by Arksey and O'Malley [23], and further advanced by Levac et al [24]. The final search strategy (See Table 1) was determined after the initial data charting searches [25] 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.

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*)))

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, *Mental Health Atlas,* (2005), indicates that although the majority of global burden of mental health disorders is in low to middle income countries, ninety percent of global mental health resources are located in high-income countries [26]. Furthermore, only 6% of the research on mental health have been published in indexed journals from these countries [27]. 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 [28].

Table 2: Inclusion and exclusion criteria

Inclusion/exclusion criteria	
1	Exclude if not written in English.
2	Exclude if published before January 1990.
3	Exclude if not empirical, not evidence based, not reviews of other studies or not a policy document/guideline (exclude commentaries, letters, book reviews).
4	Exclude if not directly or indirectly focused on mental health service users age 0-25 years (i.e. studies with parents/carers of mental health service users, service providers will be included).
5	Exclude in no focus on mental health or mental disorders. Exclude if symptoms are associated with non-mental health disorder (e.g. behavioural problems associated with ADS)
6	Exclude if is no focus beyond treatment type. The focus must include service delivery and be relevant to community care (regardless of persons or organization providing services, and severity or duration of mental health condition).
7	Exclude if services are not delivered in community settings
8	Exclude if describes children and adolescents mental health services in developing countries (according to World Economic Situation and Prospects 2015).

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 [24] 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 [29] 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 selected for final inclusion.

Table 3: Characteristics of included studies: Barriers for access to CAMHS and treatment engagement

Criterion	Characteristic	Number of studies
Year	1990-2000	3
	2001-2005	7
	2006-2010	18
	2011-2016	19
Country	Australia	9
	UK	4
	USA	29
	Canada	5
Study design/publication type	Qualitative	17
	Cross sectional	16
	Mix methods	5
	Audit	5
	Experimental	1
	Discussion paper	3
Participants/data source	Children and young people	14
	Parents	16
	MH providers	11
	MH support staff	5
	Service outcome data	8

Setting	Rural	7
	Mixed	17
	Urban	13
	Suburban	1
	Not reported	5
	Not applicable	4
Barrier for access/engagement	Availability of MH specialist services	20
	Lack of information about available services	11
	Inflexible services	9
	Waiting time	21
	Complex administrative procedures	10
	Costs associated with treatment	14
	Users' expectations of provider's attitude	18
	Barriers endorsed by primary care providers	10

**Same papers may have reported more than one barrier*

We identified 3859 papers on strategies to improve access and engagement, of which 25 were included in the review.

Table 4: Characteristics of included studies – Improving access and engagement with CAMHS

Criterion	**Characteristic**	**Number of studies**
Year	1990-2000	4
	2001-2005	4
	2006-2010	8
	2011-present	19
Country	USA	7
	Canada	3
	Australia	5
	UK	8
	Finland	1
	New Zealand	1
Study design	Comparison group study	5
	RCT	1
	Audit	7
	Prospective cohort design	1
	Cross sectional design	4
	Mixed methods	6
	Qualitative (document analysis)	1
Participants/data source	Children and young people	15
	Parents	2
	MH service staff	6
	Records/service outcome data	9
Setting	Urban	8
	Mixed	7
	Suburban	5
	Rural	1
	Not reported	5
Strategy to improve access	Providing MH services in accessible location	7
	Facilitated access	3
	Case assessment and prioritisation	7
	Strategies to increase engagement	5
	Choice and Partnership Approach	5

**Same papers may have reported more than one strategy*

3.2. *Narrative synthesis and description of findings*

3.2.1. *Service-level barriers for access and engagement*

Availability of specialist MH services

Twenty studies identified lack of availability of appropriate services as a major obstacle for connecting patients with MH difficulties with specialist services. Of those, seven were cross sectional studies using questionnaire, ten were qualitative studies involving interviews and focus groups with service users, one study used a mix of surveys and qualitative interviews, and one was a case study of service provision. Limited availability of specialised MH services was particularly cited by young people and families living in rural and remote areas. [30-34]. Traveling significant distance to see a MH specialist was a significant obstacle for parents [31, 35, 36], while young people reported transportation problems as a barrier for accessing services [37-40]. Availability of services is not only a result of its geographical location, but also refers to access to MH support that is acceptable for users and available when needed. Two studies reported users' concerns about lack of after-hours and crisis support services [30, 41], particularly when young people in crisis have to go through usual referral routes and face long wait lists to get help they need. Four studies cited lack of culturally appropriate MH services a barrier for access, especially for children and families from ethnic and racial minority groups [36, 42-45], while the same number reported language access barrier encountered by service users [44-47].

Lack of information about available services

Lack of information about available services resulting in users not knowing where to go to get help was reported in eleven studies including three qualitative studies involving interviews and focus groups with service users, five cross sectional studies using questionnaire, and three case studies of service provision. Lack of information about available services was equally prominent in studies conducted in both rural and urban locations. Four studies reported that not knowing where service is located and how to make an appointment are major barriers for adolescents seeking MH support [32, 37, 48, 49]. Not knowing where to go for MH support was also cited by a quarter out of 1948 participants of US Adolescent Health Care Access Survey [40]. One study reported that adolescents, even if they were aware of existing services, did not know how to make an appointment without approaching a school counsellor or a parent first [48]. Many of them did not want to involve an adult or did not attend school any longer, thus in these situations help-seeking was dependent on young person's prior knowledge of the service and the option of self-referral [48].

Parents also cited not knowing where to go as one of major barriers for seeking help for their children experiencing MH difficulties [50]. Results of a qualitative study examining issues for access to CAMHS in rural communities showed that in most cases families found out about available services through informal routes (i.e. from other people whose children were experiencing similar difficulties) [35].

Inflexible services

Nine studies reported inflexibility of services and lack of attempts to make it user-friendly as major obstacle for both initial access and continuous engagement with MH services. Of those, four were qualitative studies using interviews, three were cross sectional, survey based studies, one was a case study, and one study involved an audit of state mental health plans. Parents, especially when their child's treatment was ongoing, reported having difficulties with repeatedly taking time off work [50, 51], and young people found it problematic that appointments were available only within school hours [38]. One study reported that rigid rules according to which services operate caused difficulties in transferring records from one setting to another, resulting in treatment delays and disruption with taking medications due to inability to obtain prescription [52]. In another study school principals and counsellors reported that major obstacle for referring students with MH difficulties to specialist services is lack of flexibility of appointments and settings [41]

Wait times

Twenty one studies reported long wait times to be the major barrier for accessing and engaging with MH services. This included eight qualitative studies, six cross sectional studies, two studies using mixed methods, four audits of service data, and one case study. Long waiting times was the most commonly endorsed barriers cited by service users [37, 45, 48, 50, 53], healthcare professionals [54, 55] and service managers [56]. In a study by McCann et al [48] adolescents reported long wait time for an initial appointment a major obstacle for getting MH support. Due to high demand appointments had to be prioritised according to the level of urgency assessed by a clinician. Some adolescents expressed their frustration with the fact that their problems were not considered serious enough to get them seen soon, and this has deterred some from persevering with their appointment [48]. In two studies, users and parents expressed an opinion that the only way to 'jump the queue' was a child or young person doing something extreme, most commonly attempting suicide or self-harm, or threatening to harm others [30, 35]. Over 60% out of 319 primary care providers reported that difficulty or delay in getting a MH specialist appointment was a major barrier for referring their adolescent patients to specialist services [55]. School principals and counsellors also identified long waiting lists as major obstacle for students' access to MH services, and indicated that long delays in accessing services often dissuaded them from making a referral to CAMHS [41].

Evidence suggest that long waiting lists have negative impact on families' engagement with MH services. There is a strong relationship between delay in scheduling an initial appointment, the length of time between referral and appointment date, and likelihood of attending the initial consultation [57-59]. Average wait time for kept appointments was 14.5 days and after 16.5 days the likelihood of keeping an appointment started to decrease with the odds of attending declining 1.4% for each additional day of wait time [60]. In a study by Schreader, almost a half of parents of children that were being placed on a waiting list contacted another agency. Longer waiting list increased the likelihood of seeking help elsewhere with 25% of families contacting another service within the first month of being on the waiting list [61].

Complex administrative procedures

Ten studies, including five qualitative studies, four survey based cross sectional studies and one audit of service data, reported administrative procedures and multiple referral steps major barriers for connecting children and young people with MH services. Parents indicated that having to make numerous phone calls to find a clinician, make appointments, reiterate the treatment history and explain the need for a visit is a significant barrier they encounter when seeking MH support for their child [42, 62]. Having to deal with multiple referral steps to access the right service was another barrier reported by parents [50]. Service users often waited a long time to access one service only to be referred to another specialist and face another long waiting list [50]. A qualitative study examining experiences of parents seeking help for their child's MH difficulties found that parents, on average, contacted four agencies or professionals in the year preceding the study interview. Some parents were looking for help for different problems, however the majority contacted more than one agency in order to find the most appropriate treatment for the same problem [63]. In some cases, parents reported being offered a treatment they did not want for their child and declining it, to subsequently look for other options from different agencies and face another long wait for service [63].

Parents reported that overcoming administrative barriers for access to CAMHS requires advocacy work by a family member described as "being demanding, persisting, vocal, pushy, complaining, writing letters and going to the top" [35]. Parents acknowledged that they often did not get service because they did not push hard enough due to their personal style, lack of education and lack of time resulting from work obligations and parenting of other children [35].

Costs associated with treatment

Fourteen studies reported costs associated with treatment and insurance problems as significant barriers for seeking support for their children experiencing MH difficulties. Of these five were qualitative studies using interviews, seven questionnaire-based cross sectional studies, one audit of state mental health plans, and one case study. Since in the UK MH services for children are free under the National Health Service, this section reports findings from US and Australian studies. Included studies reported a range from 10% to 56% of respondents recounting costs associated with ongoing treatment, including costs of transport and organising care for other children, as a factor preventing them from engaging with services. One recent study reported that expenses associated with treatment were the highest ranked barrier endorsed by 52% of 134 parents [50]. Respondents were not aware that child MH services in Australia did not charge any fees, indicating lack of knowledge how the support system works [50]. Another study evaluating Australian *headspace* showed that although this service for young people is initially free, Government's universal public health care system covers only 12 sessions per year, which means that some young people drop off mid-treatment, as they are not able to pay for the service [48]. A similar issue was highlighted by a US study of paediatricians who reported that children discontinue treatment prematurely due to limitations enforced by insurance programs [54]. Difficulties finding MH providers accepting Medicaid insurance was recognised as the major barrier for referring children with MH difficulties from primary care to specialist services [54]. In some US studies, parents reported that dealing with insurance companies impeded or delayed their attempts to access MH services [42-44, 53, 54]. For example with some insurance plans users need to obtain pre-authorisation for child's MH treatment from a health plan representative, which requires additional time and ability to navigate through a complicated system [42].

Users' expectations of providers' attitudes

Primary care providers are in most cases the first point of contact with services for parents concerned about their child's MH. Eighteen studies reported that users' concerns about providers' attitude can be a major barrier to seeking and accessing MH support. These included six qualitative studies using interviews and focus groups, six cross sectional survey studies, three studies using mixed methods, two case studies and one audit of service outcomes data. Parents reported having concerns about MH professionals not caring about their children, being disrespectful, unfriendly, or committing the child against their will [43, 64]. Some parents reported difficulties convincing a provider that their child was having a problem [42, 65]. Ambivalent or dismissive responses from a provider discouraged some parents from seeking help further, however some reported becoming more persistent [42]. In a study of 10,688 caregivers of children with special needs including MH difficulties, 31% of participants reported that lack of shared decision making discouraged them from continuing involvement with services [53]. According to users, some primary care providers offered medications before trying other, non-pharmaceutical approaches that are, in most cases, preferred by parents [42, 43] and adolescents [52, 66]. Parents who do not want to medicate their children without reviewing other options may seek another opinion, or ignore provider's recommendation and temporarily give up on seeking help until the child's problem becomes more severe [42]. Parents of adopted children cited MH professional not recognising the extent of parental challenge and feeling like they are being blamed for their adopted child's MH problems as barriers for seeking MH support [45]. Concerns about attitudes of healthcare professionals were also raised by young people experiencing MH difficulties. In two studies adolescents reported that concerns about not being treated with respect and worries about what a provider would say or do prevented them from seeking help [40, 67]. In a study with adolescents diagnosed with depression and currently in treatment, participants who felt that their provider did not give them feedback or information, judged them as abnormal, or offered medication without discussing alternative options were less likely to comply with treatment recommendations [66]. Young people also expressed concerns about privacy and confidentiality, and the provider sharing what they revealed during a session with their parents [37, 40, 49, 67]. Discrepancies between users' and providers' perception of severity of MH difficulties reflected in cases prioritisation can also hamper patients' connection with MH services [68, 69]. One study showed that the majority of youth who considered their MH difficulty severe were not referred to specialist services, as primary care physicians did not consider their problem serious enough to require specialist consultation [69].

Service level barriers endorsed specifically by primary care providers

Ten studies examined barriers to supporting children experiencing poor MH encountered by providers working in primary care settings. Six were questionnaire based cross sectional studies, three were qualitative studies involving interviews and focus groups, and one study used a mix of qualitative and quantitative methods. Paediatricians working in primary care settings reported that they do not feel sufficiently prepared to diagnose or treat MH problems [70]. However 97% out of 181 paediatricians felt comfortable prescribing stimulant medication, 59% selective serotonin reuptake inhibitors, but only 25% antipsychotic medications [70]. One study showed that paediatricians and psychiatrists often disagreed as to the frequency with which particular MH problem should be referred. In cases of all disagreements, paediatricians indicated that the problems did not require specialist's involvement, while psychiatrists recommended referral [71].

Two studies cited lack of financial compensation for providing MH services and having to use physical health billing codes for behavioural health services as main reasons for not performing MH screening in primary care [72, 73]. Two studies identified lack of MH professionals accessible for consultations and referrals as a major barrier [36, 70], and one study reported that unavailability of paediatric MH specialists resulted in pressure to refer adolescents to adult MH specialist [55]. In a study with 319 primary care clinicians, most commonly reported barriers for referring children and young people to specialist MH services included complex authorisation procedures, burdensome authorisation paperwork, difficulties finding MH specialist accepting particular insurance plan, financial disincentives and pressure to contain costs, and physicians' panel restrictions [55]. Three studies reported lack of communication between agencies and fragmentation of services as barriers for referring young people experiencing MH difficulties from primary care to specialist MH services [36, 70, 74]. Senior managers of children MH centres endorsed funding, case complexity, waitlists, staffing and lack of integration as major barriers for providing effective and timely care [56].

3.2.2. Strategies to improve access and engagement with MH services

Providing MH services at easily accessible locations

Ten studies, including seven quantitative and three mixed methods studies, reported that providing MH services in easily accessible locations like schools, local primary care clinics or community walk-in clinics is an effective strategy to increase access and engagement, especially for users from hard to reach groups. In two studies MH services were provided weekly in schools by clinical psychologists and trainees from an outpatient, university affiliated MH clinic [75]. The first study found that children using school-based MH services did not differ in regard to clinical severity of MH problems from children seen in a central clinic, however, over a 12 months period, 98% of children attending school-based clinic were from minority population comparing to 37% in the central clinic [75]. In the second study all students (n=1413) accessing school-based services during the first year of its activity were from ethnic minority groups [76]. A pilot study evaluating the impact of establishing a school MH consultation clinic, teachers' training and seminars for parents to increase their understanding of MH issues showed that the initiative improved access to MH services for young people who otherwise would have not sought help through traditional referral pathways [77]. Engaging parents and teachers in designing school MH services results in significantly increased family engagement with services and reduces treatment drop-out rates [78].

Evidence suggest that providing MH care in primary care settings increases the number of patients receiving appropriate and timely MH support. In a study examining the effectiveness of collaborative care model in which child psychiatrists offered real-time phone consultation and, if needed, further evaluation of patients seen in a paediatric clinic, about 40% of possible referrals were resolved during phone consultation with psychiatrist or psychiatric nurse [79]. Of all youths referred to specialist clinic, 46% were only seen once for an evaluation visit and afterwards they returned to primary care paediatrician for ongoing MH treatment. The program allowed psychiatrists to influence treatment of a large number of youths with relatively common and uncomplicated MH problems. Referring those cases back to primary care increased psychiatric clinic's capacity to provide ongoing care for patients with more complex problems, and reduce wait times [79]. An RCT evaluated effectiveness of an initiative that included placing an expert team leader at each of the five participating clinics, training care managers in manualised CBT for depression, and training clinicians in evaluation and treatment of depression [80]. Patients from intervention sites had significantly higher rate of MH care and psychotherapy or counselling fewer depression symptoms, better quality of life, and higher satisfaction with care they received, comparing to patients in usual care [80].

One study showed that providing MH services to homeless in easily accessible location - an outreach clinic operating at youth crisis accommodation service - increased contact with services for those in need, and facilitated ongoing care with over a half of users attending more than one appointment [81]

Facilitated access

Results of three quantitative studies suggest that providing MH support in community walk-in clinics improves access to care for patients who are otherwise discouraged by complicated referral procedures and long waiting lists. Users attending a walk-in counselling centre found wait times more reasonable and had higher regard for counsellors' availability and service cultural sensitivity comparing to users in usual care [82]. Although walk-in clinic patients' had more severe MH problems comparing to those in usual care, they improved more quickly and required fewer appointments [82]. Some evidence suggest that self-referral is more acceptable way of accessing MH services for patients representing ethnic minority groups. A study evaluating acceptability of a self-referral MH service for Black and ethnic minority children and their families showed that this service model was more accessible for minority users comparing to usual care [83]. Similar results were found in a study evaluating self-referral MH service for Australian ethnic minority youth, however participating clinic also focused on providing culturally appropriate services, which could significantly contribute to its higher acceptability for this particular user group [84].

Case assessment and prioritisation

In seven quantitative studies, including three audits of service outcome data, assessing cases referred to MH specialist services and prioritising those that due to their severity require urgent attention was an effective strategy to reduce wait times for specialist appointments, and increase patients' flow. Two studies showed the effectiveness of a referral management system in which clinicians dedicated two days per month for evaluation appointments [85, 86]. Outcomes of these appointments were reviewed by a multidisciplinary team that decided cases' allocation and further management. Appointment slots were only given to families who confirmed their attendance. In both studies waiting times were significantly reduced [85, 86], and in one study the 'did not attend' rate decreased [85]. Another study evaluated a similar prioritisation model in which a multidisciplinary team provided up to five new referral slots per week [87]. New clients were offered up to three initial assessment appointments, followed by therapy or consultations with key agencies. Waiting time for initial appointment was reduced from 8 months to 8 weeks and a third of clients required only three sessions or fewer [87].

Standardised tools have been developed to facilitate case prioritisation using evidence-based criteria. Highland Prioritisation Criteria include six predicators of positive outcomes: having a single problem for less than 6 months, being under 5 years of age, changing schools or in exam year, being from a family with stable recent history of family composition and highly motivated to change [88]. All cases fulfilling at least four criteria were place on 'soon' waiting list, however families were required to confirm they want to wait, otherwise they were removed from the list. Introducing the criteria reduced wait time from 58 to 45 weeks and 'did not attend' rate dropped from 39% to 13% [88]. A Western Canada Waiting List (WCWL) developed and tested clinician-scored priority criteria measures, to objectively assess and compare the relative urgency of cases placed on waiting lists [89]. The initial version of WCWL prioritisation measure was developed by a panel including MH specialists, primary care physicians, and researchers. The criteria accounted for about 40% of observed variance in overall urgency ratings, and reliability assessment indicated half of the items had excellent or good interrater agreement, and test-retest reliability [89]. Cawthorpe et al proposed a Child Mental Health Priority Criteria Score (CMH-PSC) based on initially developed WCWL measure [90]. The measure, completed in 2-4 minutes, has an excellent internal validity, significantly discriminates each clinical level, and its' score is meaningfully related to clinician's perceived urgency and maximum acceptable waiting time [90]. Kaukonen et al developed and tested a Finish nationwide standardised criteria for assessing the need for non-urgent child psychiatric care [91]. The Finish Child Psychiatric Criteria Tool, covering the entire case-mix of child psychiatric disorders, has 82% sensitivity and 74% specificity, with most items at least moderately correlated with clinical necessity-for-treatment assessment [91].

Strategies to improve engagement

Five studies focused on evaluating the effectiveness of strategies developed to reduce 'did not attend' rates. One study examined the impact of a learning collaborative that provided training to MH clinic staff on two evidence-based engagement strategies: a phone-based intervention and face-to-face interview [92]. Service outcome data were examined to compare attendance rates in 1-5 month periods in a year before and after introducing engagement strategies. Implementation of described strategies resulted in increasing initial intake from 5% to 21%, while keeping subsequent appointments increased from 2% to 16% [92]. Evidence suggest that requiring patients to confirm their willingness to remain on a waiting list and to attend an initial appointment are effective strategies to reduce 'did not attend' rates [85, 86, 88]. However in one study only a quarter of families confirmed that they want to continue waiting for services. [93]. Of patients who were removed from the list 10% were re-referred in 3-20 months and their time in treatment was on average 8 month longer comparing to those who opted to continue waiting [93]. In another study, letters with information about the length of the waiting list, and a child functional assessment questionnaire with a request to return to the clinic before or during the first appointment were sent to all referred patients [94]. A reminder call was made 1-2 days before the initial visit. There were no significant differences in the first appointment attendance rates between patients who did and did not receive the letter. However patients who returned the questionnaire prior to their visit were more likely to attend, comparing to those who did not [94].

Choice and Partnership Approach (CAPA)

CAPA approach has been widely adopted in the UK, Australia and New Zealand as a strategy to increase efficient use of limited MH service resources [95-97]. CAPA is a patient management system informed by demand and capacity theory that emphasis patients' empowerment by putting them in charge of choosing a treatment they feel is most appropriate for them. Five studies (one qualitative study of service providers, two studies using mixed methods and one audit of service outcome data) examined the impact of implementing CAPA on waiting times, patient flow and users' and providers' satisfaction [95, 98]. In one study introducing CAPA virtually eliminated waiting lists and time between referral and first appointment decreased from 64 to 11 days [99]. However outcomes of CAPA evaluation involving six CAMHS teams across the UK suggest that it is beneficial and provides teams with well-structured planning model only when it is well-managed and implemented [96, 97]. If it is implemented without appropriate management it may cause administrative problems, confusion and overworking of staff [97].

4. Discussion and conclusions

4.1. Breadth of literature

The review identified a number of service-level barriers for access and engagement with MH services encountered by children, young people and their families. Most studies that examined barriers for access focused on personal-level as well as service-level barriers providing a more comprehensive picture. Barriers were examined from perspectives of different stakeholders including service users (young people and their parent/carers), primary care and MH clinicians, and service managers. Most reported studies were conducted after 2010; before year 2005, studies examining barriers for access and engagement with MH care were scarce. This reflects the lag in demand and capacity in practice to emerge in research, as well as increasing interest in barriers for access encountered by ethnic minority groups. Over 60% of reported studies were conducted in the US and only four in the UK. The majority of reported studies are questionnaire-based cross-sectional studies and qualitative studies involving semi-structured interviews and focus groups with stakeholders. The literature on strategies to improve young people's access and engagement with MH services also emerged more recently. The majority of reviewed papers were published in the UK after year 2010, and examine strategies to decrease waiting times for MH services. Audits of service outcome data and administrative case files were most frequent, followed by questionnaire-based cross sectional and comparison group studies.

4.2. Findings

One of the major barriers for seeking help with MH problems reported by both young people and their parents/carers is lack of awareness of existing MH services, and limited understanding of pathways to access appropriate care [31, 35, 37, 39, 40, 43]. This may be due to the fact that although services are available for young people and their families, they are not particularly well publicised, and potential users have to 'ask around' to find out where to seek help. Most specialised services cannot be accessed directly and referral routes are complex and hard to navigate, especially for users who are not very well equipped to negotiate the system, e.g. due to a language barrier [47] or personal style preventing parents from advocating strongly to access services they think are optimal for their child [42]. Connecting with appropriate services is often a drawn-out, time consuming process, which for parents who have work and childcare obligations can be a major barrier for seeking help [42, 50, 62]. Making MH services more visible for potential users through online presence or advertising in places often visited by young people, as well as providing step-by-step help-seeking guidelines explaining in a user-friendly manner the process of connecting with services may facilitate access to MH care. Also providing advocacy support for service users, especially more vulnerable ones who may find navigating complicated referral system particularly difficult, seems to be effective strategy to improve access to MH care [35]. Being able to get specialist appointment only during parents' working hour and children's school hours can be a major barrier for engagement with MH service, especially if young person's treatment is ongoing [38, 50]. Designing services around users' needs and preferences can potentially increase uptake and continuous engagement with service [38]. Limited availability and distant geographical location of specialist MH services are barriers for access especially prominent in rural and remote areas [37, 48]. Evidence strongly suggests that using technology to deliver MH services (e.g. video-conferencing) can be an effective way of increasing access for users who are not in a proximity to a specialist MH clinic [100]. Young people experiencing MH difficulties may not want to nor be able to involve an adult in help-seeking process [40, 48]. They are often concerned about the attitude of primary care provider they have to approach first to access specialist services [40]. One way of solving this is to enable young people to directly access MH services through self-referral, and ensuring that young people are aware of this access route. This strategy proved to effectively facilitate access for young people who were unlikely to connect with services through traditional access routes [75-78, 81, 82, 84]. Providing assessment and treatment of common MH disorders in primary care settings improves patients' access to MH care and contributes to reducing waiting times and pressure on specialised services, increasing their capacity to support patients with more complex MH needs [79, 80]. However, evidence suggests that primary care clinicians may not have sufficient knowledge to provide MH support [70] and have to deal with numerous administrative barriers when they try to connect families with specialised services [36, 55, 72-74]. Training and supporting primary care clinicians to offer initial assessment and treatment for common MH problems, and enhancing communication between primary care and children psychiatric services might improve young people's timely access to MH support. One of the most prominent barriers for seeking help with MH problems reported by a range of stakeholders is long waiting time to receive specialist care [37, 45, 48, 50, 53-56]. A number of strategies have been proposed to tackle the issue of long waiting lists, however none provides an ideal solution. Case assessment and prioritization by multidisciplinary teams based on clinical urgency often does not reflect clinicians', parents' and young persons' perception of seriousness of their problem [68, 69]. This discrepancy may, in crisis situations, drive young people to take extreme actions (i.e. attempted suicide or self-harm) to ensure quick access to services [30, 35]. Prioritization based on standardised urgency assessment measures with proven psychometric properties can be a good alternative, ensuring more objective, evidence-based allocation of cases [89-91]. Another common strategy to reduce waiting times is requiring families to confirm their willingness to remain on a waiting list or otherwise they are not offered services [85, 86, 88]. Some evidence suggest that not only do a small number of families confirm they want to continue waiting for services, but also those who are removed from the waiting list are likely to be re-referred with more severe disorder [98]. MH problems in childhood tend to persevere if not appropriately addressed [5], thus removing patients from a waiting list and delaying their connection with services is likely to have detrimental effect on their MH. Evidence suggests that engaging with families placed on a waiting list rather than just requiring them to confirm their intention to continue waiting for services is an effective strategy to increase an uptake of initial appointment and subsequent engagement with services. Brief interventions provided by intake workers are time and cost-effective and can significantly improve attendance, and thus contribute to shortening waiting times [92, 94].

4.3. Research gaps

This review identified prominent research gaps, mainly regarding methodology of conducted studies. The majority of studies examining barriers for young people's access to MH services include small samples affecting generalisability of findings. Most studies involve convenience samples of participants who have already been in contact with services for some time. Very few studies examine perspectives of young people who are considering seeking MH help for the first time [37, 40, 49, 53], but expect to encounter particular barriers that would impede access to appropriate services. Nearly 30% of studies evaluating strategies to improve access to MH services are audits of available service outcome data. They usually encompass relatively short period of time prior and after introducing an intervention (12 months at the most), thus there is no evidence on how effective particular approaches are over a longer period of time. Additionally most studies only examine the impact of strategies to improve access on waiting times and patient flow. It is possible that in a long run those strategies would have impact on clinical outcomes, patients' satisfaction, clinical and administrative staff's workload, job satisfaction and costs of providing services, but at the moment available evidence does not permit drawing conclusions about long-term impact. Controlled trials with longer term follow-up are needed to establish the long-term effectives of access improving strategies, and their impact on patient, provider and service levels.

4.4. Limitations

This scoping review has a pragmatic aim to provide a readily available evidence-base to support development and implementation of CAMHS Local Transformation Plan [20] in the East of England. It was designed to enable policy makers, commissioners and service managers to make decisions about redesigning, implementing and evaluating CAMHS within scientifically supported context, to ensure optimal outcomes. As a result, the review focuses largely on barriers for access associated with the way MH services for children and adolescents are designed, and pragmatic strategies to overcome them, therefore it may not provide a complete overview of existing evidence. Having in mind the pragmatic purpose of the review, we excluded studies where results were not, in our opinion, applicable in the UK context, mainly due to differences in the way CAMHS are designed and delivered in different countries, or populations they serve. Although mental health care systems and populations differ between the countries, this does not detract from the significance of the commonalties which we discuss. We have clearly indicated where there are issues relevant to particular countries, e.g. in payment structures. A comprehensive scoping of the literature is bound to be weighted towards the US where there is a long history of research in this area. The findings, however, clearly speak to the situation in the UK, for example, and replicate concerns raised in “Future in Mind” as well as the recent Delphi study examining priorities for CAMHS provision (Howard et al., in preparation). We excluded publications that did not focus solely on MH conditions, i.e. we excluded a large number of papers describing barriers to access to MH services for users with developmental or learning disabilities, or whose MH symptoms did not explicitly result from a MH disorder (e.g. behavioural problems in children with ADHD). Finally, since we have not assessed the quality of included evidence, the review comprises a number of studies that are not particularly strong methodologically thus their results, however promising, have to be interpreted with great caution. The review includes a number of case studies examining implementation of a particular service model or strategy to improve access and engagement with MH services. Some of these strategies produced very promising outcomes, however they were implemented and evaluated in small, homogenous organisations and over a short period of time. As a result it is hard to make predictions whether the same intervention would produce equally positive outcome if implemented in different settings and evaluated over a longer period of time. Many reported studies included very small sample of self-selected participants, increasing likelihood of biased results. Due to quality of available evidence, outcomes of this review have to be interpreted with caution. Their gravity is not sufficient to support definitive conclusions regarding optimal strategies to address most prominent service-level barriers that prevent children and young people from accessing and engaging with MH services.

We confirm that there are no known conflicts of interest associated with this publication. We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us.

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[1] NIHR CLAHRC East of England, University of Cambridge, Institute of Public Health, Douglas House, 18 Trumpington Road, Cambridge CB2 8AH, United Kingdom

Table 5: Findings – barriers for access to CAMHS and treatment engagement

Reference	Year	Country	Study design	CYP	Parents	MH providers	MH support staff	Service outcome data	Sample size	Setting	Barriers in PC	Service availability	Lack of information	Inflexible services	Waiting time	Administrative procedures	Cost	Provider's attitude
Aisbett et al	2007	Australia	Qual	x					3	Rural		x		x	x			
Allison et al	2008	Australia	CS				x		171	Mixed		x		x	x			
Allnock et al	2012	UK	MM	x			x	x	269	Mixed	x	x			x			
Bitar et al	2009	USA	Qual			x			181	Mixed	x	x		x			x	
Boyd et al	2007	Australia	CAS						NA	Rural		x	x				x	x
Boyd et al	2011	Australia	CS	x					201	Rural		x					x	
Boydell et al	2006	Canada	Qual		x				30	Rural		x	x		x	x	x	
Bringewatt, Gershoff	2010	USA	CAS						NA	NA		x	x				x	
Brown et al	2014	USA	Qual		x				20	Urban		x						x
Cohen et al	2012	USA	Qual		x				24	Mixed		x			x	x		x
Davis et al	2012	USA	CS			x			70	Mixed	x	x						
Deringe et al	2010	USA	CS		x				1301	Mixed				x			x	x
Diamond et al	2012	USA	CS			x			671	Suburban	x							
Draucker et al	2005	USA	Qual	x	x	x			63	Urban								x
Flisher et al	1997	USA	MM	x	x				1285	Urban								x
Galluci et al	2005	USA	Aud					x	5901	NA					x			
Golding	2010	USA	CAS						NA	NA			x	x	x			x
Gould et al	2012	USA	Aud					x	NA	NA				x	x	x	x	
Hernan et al	2010	Australia	CS	x					74	Rural		x	x		x		x	x
Honingfield, McKay	2006	USA	CS			x			124	Mixed	x		x					
Iskra et al	2015	Australia	CS		x				134	Urban			x	x	x	x	x	
Kerkorian et al	2006	USA	CS		x				253	Mixed								x
McDonald et al	2005	Australia	Qual			x			NR	NR	x	x						
McGuire, Gushard-Pine	2005	UK	Aud					x	NR	Urban								x
McCann, Lubman	2012	Australia	Qual	x					25	Urban			x		x		x	
Muir et al	2012	Australia	Qual	x					168	Mixed		x		x				
Oke, Mayer	2001	UK	CS			x			50	Urban	x							
Oruche et al	2014	USA	Qual	x	x				24	Urban				x	x	x		x
Pfefferle	2007	USA	CS			x			596	Mixed	x				x		x	
Pullmann et al	2010	USA	Qual		x		x		17	Rural		x						
Radovic et al	2014	USA	CS			x			48	Mixed						x	x	
Reid et al	2011	Canada	Qual		x				100	Mixed					x	x		
Reid, Brown	2008	Canada	Qual				x		16	Urban	x				x	x		
Richardson	2001	USA	CS		x				235	Urban		x	x			x		x
Sakai et al	2014	USA	Qual	x					28	NR		x	x				x	
Samargia et al	2006	Canada	CS	x					1948	Mixed		x	x				x	x
Schraeder, Reid et al	2014	Canada	Qual		x				273	Urban					x			
Sherman et al	2008	USA	Aud					x	1317	Rural					x			
Stern, Brown	1994	USA	MM		x			x	809	Urban					x			
Stevens et al	2006	USA	MM		x			x	186	Mixed								x
Stiffman et al	2000	USA	Qual	x		x			1014	NR		x						x
Vohra et al	2014	USA	CS		x				10688	Mixed					x	x		x

Walders et al	2003	USA	CS			x			319	Mixed	x	x			x			
Walsh et al	2011	UK	MM	x					44	NR								x
Westin et al	2012	USA	Aud					x	2054	NR					x			
Williams et al	2013	USA	Exp				x		NA	Mixed								
Wisdom et al	2006	USA	Qual	x					22	Urban								x

CYP – children, young people

RCT – randomised controlled trial

CGS – comparison group study

CohS – cohort study

CS – cross sectional

Aud – audit

Qual – qualitative

CAS – case study

MM – mixed methods

NR – not reported

NA – not applicable

Table 6: Finding – Improving access and engagement with CAMHS

Authors	Year	Country	Study design	CYP	Parents	Records/ service outcomes	MH service staff	Sample size	Setting	Providing MH services in accessible location	Facilitated access	Case assessment and prioritisation	Strategies to increase engagement	CAPA
Armbruster et al	1997	USA	CGS	x				348	Urban	x				
Asarnow et al	2005	USA	RCT	x				418	NR	x				
Atkins et al	2003	USA	MM	x	x	x		NR	Urban	x				
Aupont et al	2012	USA	CohS	x				239	NR	x				
Barwick et al	2013	Canada	CGS	x				172	Urban		x			
Bear et al	2014	USA	CS	x				1258	Mixed	x				
Cavaleri et al	2009	USA	MM	x	x	x		60 CYP, 12 staff	Urban				x	
Cawthorpe et al	2007	Canada	CS	x				497	NR			x		
Clark et al	2014	Australia	CGS	x				581	NR		x			
Clemente et al	2006	UK	CGS	x			x	267	Urban			x	x	
Dixon et al	2011	Australia	MM			x	x	29	Urban	x				
Eapen et al	2012	Australia	Aud			x		NR	Urban	x				
Fatimilehin	2007	UK	MM	x	x		x	90	Urban		x			
Fuggle et al	2015	USA	MM	x			x	54 CYP, 12 staff	Urban					x
Jones et al	2000	UK	Aud			x		115	Urban			x		
Kaukonen et al	2010	Finland	CS	x				949	Mixed			x		
Naughton et al	2015	Australia	Qual			x		NA	Rural					x
Parker, Froese	1992	Australia	CGS	x				385	Urban				x	
Robotham	2009	UK	MM				x	315	Mixed					x
Robotham et al	2010	UK	MM				x	315	Mixed					x
Smith et al	2002	Canada	CS	x			x	817 CYP, 92 staff	Mixed			x		
Walker	1998	New Zealand	Aud			x		143	NR				x	
Wilson et al	2015	UK	Aud			x		2896	Mixed					x
Woodhouse	2006	UK	Aud			x		NR	Urban			x	x	
York et al	2004	UK	Aud			x		103	Urban			x		

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