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The effectiveness of interventions aimed at improving access to health and mental health services for looked after children and young people: a systematic review

Short title: Improving service access for looked after children

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ABSTRACT

Background: Compared with children and young people in the general population, looked after children and young people (LACYP) are more likely to experience behavioural, physical and psychological problems. Consequently, LACYP are likely to have greater need of health and mental health services to address any specific problems. This systematic review aimed to identify and synthesise evidence on the effectiveness of interventions to improve access to services accessed by LACYP.

Methods: Searches of health, social science and social care databases were conducted and records were screened for relevance.

Results: Five studies were included (four prospective cohort studies and one non-comparative study). There was considerable variation in terms of the services, interventions and outcomes reported.

Conclusions: Little appropriate evidence was identified by this review, suggesting that the evidence base is at a very early stage.

1 INTRODUCTION

Children and young people are placed outside their parents' homes for many reasons. These include physical abuse, sexual abuse, emotional or psychological abuse, various types of neglect and other circumstances that prevent parents from adequately caring for their children. Most looked after children and young people (LACYP) will have been exposed to multiple risks before entering care and these risks are associated with poor long-term outcomes. Compared with children and young people in the general population, LACYP are more likely to experience behavioural, physical and psychological problems (Meltzer, Corbin, Gatward, Goodman & Ford, 2003). Consequently, they are likely to have greater need of health and mental health services to address any specific physical and mental health problems. Service provision among LACYP, however, does not always match this greater need. For example, in the UK, although LACYP are required by law to have a health assessment at the start of each placement (Department of Health 2002a) with annual checks desirable (Department of Health 2002b), research suggests fewer LACYP than this actually have a medical examination and far fewer LACYP than children who are not looked after are registered with a general practitioner (GP) (Rodrigues 2004).

Incomplete medical histories can mean that common physical and mental health problems are not identified or adequately managed. In addition, few LACYP view annual medical assessments in a positive light and once they are judged to have 'sufficient understanding' may refuse to attend, although what constitutes understanding is not clear (Department Of Health 2002a). LACYP who are excluded from school may not be able to access any health or mental health service provided there (including social, health and personal education), and broken placements can result in incomplete health information and treatment as children and young people move between GPs (Richardson 2002).

In addition, LACYP may not have advocates (birth parents or stable foster parents) that can request assessment and treatment (Polnay, Glaser & Rao 1996). Other professionals that could act on their behalf such as GPs or teachers may be absent at times of placement breakdown and transition (Arcelus, Bellerby & Vostanis 1999). Thus the proportion of LACYP accessing services they need, both specialist and universal, is likely to be lower than among the general population of children and young people. A previous correlates review suggested that comprehensive health assessment could improve LACYP's chances of being referred to an appropriate service, although a systematic and exhaustive search and synthesis had not been conducted (Jones et al., 2011). Given the greater need of and contrasting lower access to services in LACYP than among birth or adopted children, there is a need to

synthesise the available evidence on interventions aimed at improving access in this population.

1.1 Aim

The review aimed to identify and synthesise evidence that evaluated the effectiveness of interventions to improve access to specialist or universal (available to any child or young person) services among LACYP.

2 METHODS

2.1 Searching and screening

Research on LACYP is distributed across a wide range of bibliographic databases in the fields of health, social science and social care (Clapton 2010). Our approach to capturing relevant material was to search 18 key bibliographic databases from these fields. In the first stage, we used search terms relating to the population, such as 'looked after child/children', 'children in care', 'foster care' and 'care leaver'. These databases were Applied Social Sciences Information and Abstracts (ASSIA), Australian Family and Society Abstracts, British Educational Index (BEI), Campbell Collaboration C2 Library, Current Education and children's services Research in the UK (CERUK Plus), ChildData, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus), EMBASE, Health Management Information Consortium (HMIC), International Bibliography of the Social Sciences (IBSS), JSTOR, Medline, PsycInfo, Social Care Online, Social Services Abstracts, Social Work Abstracts and Zetoc. The full search strategy is available from the full report informing NICE guidance (Jones et al., 2010). Searches were limited to 1990 onwards and were not restricted by language, study type or place of publication. The combined search output at the end of this stage was 20,000 records on the population of LACYP. This population database was then searched using terms for service use and access (Jones et al., 2010). The search terms were drawn up by the first four authors, based on papers included in a previous correlates review, which broadly examined factors associated with outcomes among LACYP (Jones et al., 2011) and knowledge of the review topic. This process resulted in 5114 retrieved citations (excluding duplicates).

Searches of reference lists and citation searches were conducted on all included papers. Citation searching was undertaken in Web of Science Cited Reference Search and Google Scholar and was not limited by date, language, place of publication or study type. This process resulted in 36 novel retrieved citations, of which none were included.

Retrieved citations were screened using the following inclusion/exclusion criteria:

The population comprised LACYP, including adults who were LACYP if information on their access to services in childhood was collected. The focus was on any intervention designed with the purpose of improving access to any specialist or universal service accessed by LACYP during their time in care. Treatment foster care (also described as therapeutic foster care), which typically includes approaches aimed at enhancing access to services, was not included, because this approach consists of a complete package of care rather than a specific intervention designed to improve access to services. The comparison group comprised LACYP or former LACYP with usual or no access. The main outcome examined was access to the service in question. Also considered were outcomes relating to the physical and emotional health and well-being of LACYP, longer-term outcomes in adult life and intermediate outcomes (including placement stability), as reported by studies.

Study types to be considered were: randomised controlled trials, non-randomised controlled trials, case control studies, prospective cohort studies, retrospective cohort studies (of adults who were previously LACYP) and non-comparative pre-post studies.

Screening for relevance was initially undertaken at title and/or abstract level and then full paper level. Study selection was made by one reviewer, however a random selection of abstracts and full papers (28 records or 5% of the records whose abstracts were inspected) were sifted independently by two reviewers (the first two authors). No differences were found between reviewers' judgements. Overall, 4602 records were excluded at title stage, 401 were excluded at abstract stage, 142 were excluded at full paper stage and five were included (see Figure 1).

2.2 Study quality

Study quality was assessed using the checklists and guidance provided in the NICE Centre for Public Health Excellence Methods Manual (National Institute for Health and Clinical Excellence (NICE) 2006), which assesses studies according to various aspects of design, sampling, measurement, analysis and reporting. Greater consideration was given to the performance of the study on criteria fundamental to the robustness of the findings. Study quality did not determine inclusion into or exclusion from the review. Studies were graded with ++, + or -, where ++ indicates that all or most of the criteria have been fulfilled and where they have not been fulfilled the conclusions are thought very unlikely to alter; + indicates that some of the criteria have been fulfilled and those that have not been fulfilled are unlikely to alter the conclusions; and - indicates that few or no criteria have been fulfilled and the conclusions of the study are thought likely or very likely to alter. Study quality was assessed by both reviewers; any disagreements on study quality were to be resolved by

discussion with reference to third party in the event of no resolution. There was no disagreement on the grading of studies.

3 RESULTS

Five studies were identified as meeting inclusion criteria: four US prospective cohort studies and one UK non-comparative study (see Table 1). No studies were rated ++ on quality, three US prospective cohort studies were rated + (Horwitz, Owens, & Simms 2000+; Kienberger Jaudes, Bilaver, Goerge, Masterson, & Catania 2004+; Risley-Curtiss & Stites 2007+), one US prospective cohort study was rated – (Collado & Levine 2007-) and one UK non-comparative study was rated – (Ashton-Key & Jorge 2003-). These studies are described in Section 3.1.

3.1 Study characteristics

Interventions to improve access to services varied considerably across studies (see Tables 1 and 2). Collado & Levine (2007) placed one full-time psychotherapist on-site at two foster care agencies in New York City. In the Horwitz et al. (2000) study young children newly entering foster care were provided with a comprehensive multidisciplinary assessment, compared with usual care. The Kienberger Jaudes et al. (2004) study employed a comprehensive programme of medical case management in Cook County Illinois. Risley-Curtiss and Stites (2007) examined whether providing the medical professional undertaking initial health assessment of LACYP with all reasonably available medical information improved the provision and timeliness of health assessments. Finally, Ashton-Key and Jorge (2003) provided social services with a detailed immunisation history for every looked after child where the details were known in order to improve access to immunisations.

The ages of the children studied varied between the studies, with three US prospective cohort studies and one UK non-comparative study reporting a broad age range up to the age of 18 and one US prospective cohort study reporting a much narrower age range focusing on younger children up to the age of six years (see Table 1). The setting, type of intervention and type of service accessed varied considerably, making direct comparison and synthesis of data inappropriate. In addition, much information (e.g. mean age of LACYP, initial response rate and rate of attrition at follow-up) was not reported for some studies.

3.2 Effectiveness of interventions to improve access to services

3.2.1 Access to services overall

Only one study reported on an intervention aimed at improving access to a range of services. Horwitz et al. (2000) (+) found that the provision of specialised multidisciplinary assessments

for children entering the care system (compared with usual medical assessments) had a positive impact on access to all services in general. Not only were a greater proportion of the intervention group referred to services relative to the comparison group (71.0% vs. 43.1%; $p=0.002$), but of those referred to services, a greater proportion of intervention group participants than comparison group participants had received the relevant service at 6-month follow-up (68.2% vs. 44.0%; $p=0.049$). However, this effect was not statistically significant at 12-month follow-up (77.3% vs. 60.0%; $p=0.128$), suggesting that such an intervention may only have short-term effectiveness. These findings are in contrast to baseline levels of access, where a statistically significantly smaller proportion of the intervention group were receiving any service than the comparison group (38.7% vs. 62.1%; $p=0.011$). It is difficult to assess the impact of the intervention as differences between groups across time were not compared statistically and baseline levels of access were not accounted for in analyses.

3.2.2 Mental health service access

Two studies examined interventions aimed at improving access to mental health services, and the findings of these studies report disparate findings. Horwitz et al. (2000) (+) found no statistically significant difference between LACYP receiving and not receiving a comprehensive multidisciplinary assessment in referral to mental health services among those with an identified need (43.5% vs. 37.5%, $p=0.768$). Meanwhile, Kienberger Jaudes et al. (2004) (+) found that LACYP receiving a comprehensive medical case management programme were more likely than those receiving usual care to receive mental health services in the form of psychiatric clinic services (5.5% vs. 4.1%, adjusted OR 1.28, $p<0.01$). A similar percentage of the intervention and comparison groups received mental health services (14.3% vs. 14.5%), however after adjustment for confounders those receiving the programme were apparently more likely to receive mental health services (adjusted OR 1.49, $p<0.01$) (Kienberger Jaudes et al. 2004+).

3.2.3 General health service access

Four studies evaluated interventions aimed at improving access to general health services, the findings of which also differ between studies. Horwitz et al. (2000) (+) found no statistically significant difference between the proportion of LACYP with an identified need receiving and not receiving a comprehensive multidisciplinary assessment being referred to medical services (26.3% vs. 40.9%, $p=0.326$). Kienberger Jaudes et al. (2004) (+), however, reported that LACYP receiving a comprehensive medical case management programme were more likely than those receiving usual care to receive physician services (71.1% vs. 50.7%, adjusted OR 2.20, $p<0.01$), as well as being more likely to receive hearing examinations (13.5% vs. 10.7%, adjusted OR 1.22, $p<0.01$) and eye examinations (18.9% vs 16.8%, adjusted OR 1.27, $p<0.01$).

Ashton-Key and Jorge (2003) (-) examined the effect of providing social services with information on immunisation status for LACYP on uptake and reported a non-statistically significant decrease in immunisation uptake rates from baseline to 12 months post-intervention (60.3% vs. 55.9%, statistical test and *p*-value not reported). There was, however, no comparison condition in this study.

Risley-Curtiss and Stites (2007) (+) examined the impact of providing the professional undertaking initial health assessments upon entry into care with all reasonably available medical records, and found that LACYP in the intervention group were more likely to receive their initial health assessment within 14 days than those in the control group, both for urban areas (58.0% vs 13.4%, *p*<0.01) and rural areas (64.1 % vs 10.8%, *p*<0.01). Similar results were reported for receiving the initial health assessment within 30 days (urban 76.0% vs. 16.0%, *p*<0.01; rural 80.3% vs. 13.8%, *p*<0.01) and health examinations completed by the end of the 12-month study period (urban 92.0% vs. 34.2%, *p*<0.01; rural 88.0% vs. 13.8%, *p*<0.01).

3.2.4 Developmental and educational service access

Only one study examined the effectiveness of an intervention for increasing access to developmental and educational services. Horwitz et al. (2000) (+) found no statistically significant difference in the proportion with an identified need being referred to educational services between those receiving a comprehensive multidisciplinary assessment and those receiving customary assessments (21.0% vs. 7.1%, *p*=0.270), nor between intervention and comparison groups for rates of referral to developmental services (42.9% vs. 0%, *p*=0.064).

3.2.5 Effects of interventions on placement stability

Only one study examined placement stability as an outcome. Collado and Levine (2007) (-) evaluated the placement of mental health clinicians onsite at foster care agencies with the aim of improving access to services; the impact of this intervention on access was not measured, however its impact on placement stability was. Fewer LACYP in the intervention condition experienced placement transfers than those in the comparison condition (6.5% vs. 30.3%), although statistical analysis and significance of this effect was not reported.

4 DISCUSSION

A modest amount of evidence has been identified regarding the effectiveness of interventions to improve access to services for LACYP. Tentative conclusions can be drawn from the findings of these five studies, however there was wide variation in services, interventions and outcomes reported, with no two studies examining the impact of the same intervention. This variability highlights a significant gap in approaches to the study of this small but vulnerable

group and may further compound the health inequalities they already experience (NICE 2010). Combining standardised measures with appropriate qualitative methodologies within rigorous study designs would allow more robust statistical modelling and further inform service provision (NICE 2010).

Overall, sharing health information by the provision of all available medical records to professionals undertaking initial health assessments appeared to be effective, and placing a mental health clinician onsite at foster care agencies to improve access to services appeared to have a beneficial effect on placement stability, although only one study investigated each of these interventions (both of reasonable (+) quality). One study of reasonable (+) quality found provision of comprehensive multidisciplinary medical assessment demonstrated effectiveness (a comprehensive case management programme), whereas another study of poor (-) quality (involving a comprehensive multidisciplinary assessment) did not. Providing information on the immunisation status of LACYP did not appear to be effective at increasing access, although only one study investigated the impact of this intervention and the study was of poor (-) quality, lacking a comparison condition. Therefore it is difficult to draw any conclusions about the types of interventions that are more and less effective until further evidence emerges.

Information sharing may be an important element of any intervention to improve access to services, although the findings of this review and additional evidence (NICE 2007) suggest that provision of information alone is not sufficient to ensure appropriate and comprehensive health assessments and referrals (NICE 2010). Likewise, the effectiveness of providing more intensive assessments on increasing access to services may depend on other factors, such as the acceptability of the service impacting attendance at assessments. Reported UK figures for uptake of assessments appear to vary considerably from 25% (Butler & Payne 1997) to 64% (Rodrigues 2004), although the reasons for such variation are unclear. Figures for medical assessments among LACYP in other countries such as the US are likely to differ from UK figures, and this should be borne in mind when considering the findings of this review, most of which are from US studies. Indeed, applicability of the findings of this review beyond the US context (which can vary considerably from state to state in any case) is a more general issue that warrants consideration as the only UK study was of poor quality and thus the conclusions drawn are fundamentally based on US evidence.

It is feasible that the nature of the service itself affects access, through factors such as opening times or locations and perceptions about the nature of the service as a specialist service only for LACYP or a universal service that all young people can attend. The attitudes and communication style of the staff themselves have also been identified as a possible barrier (Social Care Institute for Excellence 2005). It may be possible to improve access by

addressing known barriers. For example, if visiting the GP or family physician for a medical assessment is a barrier to attendance then it may be possible to improve access by offering a medical assessment conducted by another health professional. Indeed, there is evidence to suggest that a nurse-based system of health interviews is acceptable to LACYP and should be considered for annual assessment (Dunnett & Payne 2000; Richardson 2002). However, such propositions can only be regarded as viable solutions when they have been evaluated as part of a systematic study of effectiveness within the appropriate age range.

Additional problems related to gaining access to a service can include identification of need for a service, length of waiting time to receive the service, the role of carers and other agents (e.g. social workers, teachers, mentors, other advocates) and how information is shared. In terms of need, there is some evidence to suggest that the level of service provision among LACYP does not match the level of need in this population. With particular reference to mental health services, the need is often greater than the provision of service (Leslie, Hurlburt, Landsverk, Barth & Slymen 2004).

The wait to access a service can also be an issue, particularly for mental health assessments. Waiting time for an assessment can be lengthy, sometimes as much as a year (Blower, Addo, Hodgson, Lamington & Towlson 2004), during which time it is likely that a child's health may deteriorate further. Waiting time was not explicitly taken into account by any of the studies reviewed, and should be considered by future research.

Given the lack of stability in living arrangements for many LACYP, it is feasible that placement stability could improve access to a wide range of specialist and universal services for LACYP. No studies meeting the inclusion criteria for the review examined the impact of placement stability on access to different levels of service or the impact of availability and access to appropriate and comprehensive health and mental health service access on placement stability. The Mental Health Foundation suggest that stability and continuity of care are important protective factors, linked with positive outcomes such as relationship skills, educational achievements and employment (Richardson 2002). A lack of stability and continuity of care has also been associated with poor access to services among LACYP with a high level of need (Stanley, Riordan & Alaszewski 2005).

UK research has suggested that LACYP do not have sufficient or timely access to mental health services. Studies report a major contributory factor to be placement instability. Evidence suggests that many services will not accept LACYP for therapy until they are assured the child or young person is in a home environment with the same carers for an extended period of time, or that both the carer and child or young person attends the service. Other factors include placement changes impacting on the child's place on the waiting list or

the child or young person being moved from one local authority to another (Callaghan 2003; McAuley & Young 2006; Richardson 2002; Street & Davies 2002). The emotional and mental health of children and young people who may have already experienced trauma, loss and separation prior to entry into care together with insufficient support or training for professional carers may contribute to a placement breakdown and requests for the child to be moved (Oosterman 2007; Sallnas, Vinnerljung & Westermarck 2004). It is acknowledged that lack of timely and appropriate interventions from specialist mental health services can compound or create a circle of LACYP with emotional and behavioural problems unable to receive appropriate treatment or help from services due to placement instability but continuing to experience placement disruption because of their unresolved or untreated emotional distress and behavioural difficulties. The current review identified one study examining placement stability, which found a positive impact of placing mental health clinicians onsite at foster care agencies on placement stability, although further robust research with baseline data and a control sample is warranted to corroborate this finding and inform commissioning and provision of services.

The present review has highlighted several gaps in the evidence examining the effectiveness of access to services for this small but vulnerable population of children and young people in general. There is an overall dearth of any evaluative evidence about the effectiveness of particular interventions aimed at improving access to such services where they exist. Of particular concern is the absence of any systematic research on availability or improvements to access to services for LACYP from ethnic minorities (including travelling communities), who are gay or lesbian, unaccompanied young asylum seekers with looked after status or LACYP with disabilities or complex needs, all of whom have additional, particular needs in addition to being looked after by the local authority. Indeed, unaccompanied young asylum seekers may be a particularly important subpopulation of LACYP as evidence indicates they have particular, additional difficulty in accessing universal and specialist health services and education (Fiddy 2003). Furthermore, the evidence reviewed did not examine whether different types of placement (local authority carers, private fostering agency carers, residential homes) have a differential impact on access, nor have any long-term studies been undertaken.

4.1 Conclusions

The evidence base for the effectiveness of interventions aimed at improving health and mental health service access for LACYP is at a very early stage, and little appropriate evidence was identified by this review. The five included studies provide some evidence for the effectiveness of a limited range of interventions, but weaknesses in study design limit the strength of conclusions.

LACYP are a small but vulnerable population (Meltzer et al. 2003), who experience major health inequalities. They often have increased need of health, mental health, developmental and educational services. Provision of appropriate access and delivery of services (including support) to LACYP and their carers requires high quality, effective multi-agency service design with integrated information sharing protocols as standard practice, between all agencies involved in the care of LACYP. There is a need for more rigorous, systematic, collaborative research in this area that to reflect the complex range of needs of children and young people at the heart of the care system. Of equal importance is the recognition of the need to provide information about the successes and limitations of services to inform commissioners faced with difficult decisions about resource allocation.

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6 KEY MESSAGES

The effectiveness of interventions to improve access to services is currently inconclusive. Good quality research is needed to formally examine the impact of interventions to improve access to services for looked after children and young people on access, health and wellbeing.

Research focusing on the impact of interventions to improve access to services among looked after children and young people from minority ethnic groups, unaccompanied young asylum seekers and/or those with disabilities is needed.

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Table 1: Intervention and study characteristics by study

Characteristic	Cohort studies				Non-comparative studies
	Collado 2007 (-)	Horwitz 2000 (+)	Kienberger Jaudes 2004 (+)	Risley-Curtiss 2007 (+)	Ashton-Key 2003 (-)
<i>Country</i>	US	US	US	US	UK
<i>Sample size</i>	108 (just intervention)	120	47,031	2,507	136
<i>Design</i>	Prospective cohort	Prospective cohort	Prospective cohort	Prospective cohort	Prospective pre-post
<i>Control condition</i>	Overall figures within the same city	Children received evaluation but results not shared	Customary medical examinations	Information not shared	N/A
<i>Age range of LACYP</i>	4-17 years	11-76 months	0-16 years	Up to 18 years	16 months-17 years
<i>Mean age of LACYP</i>	NR	NR	NR	NR	NR
<i>Type of service</i>	Mental health	Mental health, medical, developmental & educational services as needed	Physician, psychiatric clinic and mental health services, as well as hearing and eye examinations as needed	Initial health examination	Immunisation
<i>Setting</i>	2 foster care sites within New York City	Entry into foster care in 1 town in Connecticut	Entry into foster care in 1 county in Illinois	Entry into foster care in four US counties	Single urban unitary authority area
<i>Intervention</i>	Placing mental health clinicians onsite at foster care agencies to provide a service to the LACYP, engaged with all officials and professionals involved in the care of each LACYP. Team-building activities were organised and implemented, involving all support staff at all levels and linking mental health and foster care agencies together within a 'system' of care. Therapists trained foster carers and caseworkers on relevant mental health issues and the mental health treatment process as well as contributing to staff meetings.	Care provided in a comprehensive foster care clinic by staff from five independent community agencies and involved an interview with the foster carer, a complete medical examination, developmental assessment, psychological assessment, speech and language assessment and motor evaluation.	The programme comprised initial health screening by a doctor within 24 hours of entering care and before foster home placement, along with a comprehensive health evaluation, including mental health, developmental, alcohol and substance abuse screening where appropriate, within 21 days of entering care. LACYP under the age of six receive medical case management by community-based agencies and LACYP over six receive this from their welfare worker.	Providing information on all reasonably available medical records to the medical provider	Providing social services with immunisation status of LACYP
<i>Measurement Points</i>	Follow-up at 2.5-3 years	Baseline assessment (T1), with follow-up at 6 months (T2) and 12 months (T3)	Follow-up at 1 year	Follow-up at 1 year	Baseline (T1), with follow-up at 1 year (T2)
<i>Initial response / inclusion rate</i>	NR	100%	100%	100%	54.0% (136/252)
<i>Rate of attrition at final follow-up</i>	NR	NR	NR	NR	0%

NR = not reported

Table 2: Measurement used for outcomes by each study

Outcome	Controlled studies				Non-comparative studies
	Collado -	Horwitz +	Kienberger Jaudes +	Risley-Curtiss +	Ashton-Key -
<i>Access to services</i>		Number who received services, percentage of those for whom services were recommended who received the service (both overall and for mental health, medical, developmental & educational services)	Percentage who received services, (physician services, psychiatric clinic services, mental health services, hearing examinations and eye examinations) through computerised Medicaid paid claims	Number and percentage of children receiving health examination within 14 days and 30 days after entering care and at end of the year long study period (through computerised records)	Number and percentage of children up to date with immunisation
<i>Referral to Services</i>		Number and percentage of children referred to a services			
<i>Placement stability</i>	Number and percentage of children experiencing placement transfer				

Figure 1: Flow diagram of study selection

