

REVIEW ARTICLE

Organisational models of health services for children and adolescents in out-of-home care: Health technology assessment

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Abstract

Aim: Decades of research confirm that children and adolescents in out-of-home care (foster family, residential care) have much greater health care needs than their peers. A systematic literature review was conducted to evaluate organisational health care models for this vulnerable group.

Methods: A systematic literature search was undertaken of the following databases: Academic Search Elite, CENTRAL, Cochrane Database of Systematic Reviews, Cinahl, DARE, ERIC, HTA, PsycInfo, Psychology and Behavioural Sciences Collection, PubMed, SocIndex. Randomised and non-randomised controlled trials were to be included. Two pairs of reviewers independently assessed abstracts of the identified published papers. Abstracts meeting the inclusion criteria were ordered in full text. Each article was reviewed independently, by pairs of reviewers. A joint assessment was made based on the inclusion criteria and relevance. Cases of disagreement were resolved by consensus discussion.

Results: No study with low or medium risk of bias was identified.

Conclusion: In the absence of studies of acceptable quality, it is not possible to assess the impact of organisational models intended to ensure adequate health and dental care for children and adolescents in out-of-home care. Therefore, well-designed follow-up studies should be conducted following the implementation of such models.

KEYWORDS

health care interventions, utilisation of health care, systematic review, foster care, dental

Abbreviations: PICO, Population, Intervention, Control, Outcome; SBU, Swedish Agency for Health Technology Assessment and Assessment of Social Services; OHC, Out-of-home care; HTA, Health Technology Assessment; GRADE, Grading of Recommendations Assessment, Development and Evaluation; RCT, randomised controlled trial; CRC, United Nations Convention on the Rights of the Child.

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1 | INTRODUCTION

Studies from Scandinavia, the UK and the United States show that 3-6 per cent of all children will be placed in societal out-of-home care (OHC; foster family and residential care) before the age of 18.¹⁻⁴ Eurochild (2010) estimated that in the EU-countries, around one million children were in OHC on a given day.⁵ For decades, studies from Europe, North America and Australia have consistently reported that these children have significantly greater health problems and greater health care needs than their peers in the general population. This applies not only to somatic health,^{6,8-17,19-24,27-37} but also to dental health^{18,26,27,29,38-42} and mental health.^{7,25,43-72}

Children and adolescents in OHC comprise a vulnerable subpopulation, for whom society de facto has assumed parental responsibility (in loco parentis). However, despite extensive reporting of high rates of unmet health care needs, surprisingly, little seems to be known about effective strategies for provision of health care to children and adolescents in OHC.

In Nordic countries (Sweden, Denmark, Norway, Finland and Iceland) child welfare legislation and in the present review, OHC includes placement of severely anti-social children and adolescents in secure units and other forms of residential care.

1.1 | Promising initiatives

In a report to the EU-commission, the authors identified four promising models of 'good practice'.⁷³ Supplement S4 presents a summary of these models.

In this context, a systematic literature review was conducted, of studies evaluating models for delivery of health services to children in OHC.

1.2 | Purpose of the systematic review

The protocol for this systematic review was registered in PROSPERO CRD42016049484, available at <https://www.crd.york.ac.uk/prosp/ero/> and was conducted as a project by the Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU).⁷⁴

The purpose was to evaluate organisational models for systematic delivery of health and dental care to children and adolescents in OHC, with special reference to the following questions:

- What are the effects of organisational models intended to ensure that OHC children receive health and dental care?
- Which are the core ethical, social and legal issues to be considered when selecting organisational models?

2 | MATERIALS AND METHODS

Eligibility (inclusion/exclusion) criteria were specified using the population, intervention, comparison and outcome approach (PICO).

Key notes

- Children in out-of-home care have much greater health care needs than their peers.
- In our systematic literature review, no study with low or medium risk of bias was identified.
- Well-designed follow-up studies should be conducted following the implementation of models for health care delivery.

2.1 | Inclusion criteria

Population: Children/adolescents to age 17 who are about to enter OHC or are already in OHC.

Intervention: Organisational models for delivery of health and dental care to children and adolescents in OHC.

Control intervention: No restriction.

Efficacy Endpoints: Access to health and dental care.

Types of Studies: Systematic reviews, randomised controlled trials (RCT) and non-randomised studies with pre-and post-measurement of outcome.

Follow-up time: Not specified.

Study size: Not specified.

Languages: Swedish, Norwegian, Danish, English, Spanish, French and German.

Search period: From 1990 to March 2018.

2.2 | Exclusion criteria

Studies without a control group and without pre-and post-measurement of outcome.

2.3 | Literature search and procedure

Systematic search strategies were designed and implemented by an information specialist, in consultation with the review team. The focus of the searches was broad and comprehensive, particularly with respect to interventions. The following databases were searched: Academic Search Elite (EBSCO), CENTRAL, Cochrane Database of Systematic Reviews, Cinahl (EBSCO), DARE, ERIC (EBSCO), HTA, PsycINFO (EBSCO), Psychology and Behavioural Sciences Collection (EBSCO), PubMed (NLM) and SocIndex (EBSCO) (Supplement S1). The final search was conducted in March 2018. Reference lists were controlled. No language restrictions were applied in the literature search.

2.4 | Screening of abstracts search

Two pairs of authors screened the search results (title and abstract) independently, according to the defined inclusion and exclusion criteria. If at least one reviewer considered an abstract relevant, the paper was included and read in full text.

2.5 | Assessment of risk of bias and data extraction

The risk of bias was assessed with respect to selection, performance, detection, attrition, reporting and conflict of interest, according to the SBU standardised checklists for assessing how well studies meet basic quality criteria. This checklist is similar to the Cochrane checklist (<http://www.cochrane.org/>).⁷⁵ For bias assessment regarding systematic reviews, the AMSTAR instrument was used.⁷⁶ The quality of included studies (ie risk of bias) was rated as high, moderate or low. Only studies with moderate to low risk of bias were considered for grading of scientific evidence and conclusions. Any disagreements with respect to the quality rating of individual studies were resolved by consensus within the reviewer group. Thereafter, data were extracted from the included publications. All recorded extracted data were checked by the authors in pairs and were included only after consensus discussions. All decisions were documented.

2.6 | Grading of certainty

The quality of the evidence for outcome measures was assessed according to the Grading of Recommendations Assessment, Development and Evaluation (GRADE) system.⁷⁷

3 | RESULTS OF THE SYSTEMATIC REVIEW

The database searches identified 14 576 abstracts. A further nine studies were identified through manual searching, giving a grand

total of 14 585 papers. Figure 1 shows the total number of abstracts and studies identified in the searches.

3.1 | Systematic reviews

With respect to systematic reviews of studies investigating the effects of organisational models for provision of health and dental care to children and adolescents in OHC, no reviews with low or medium risk of bias were identified.

3.2 | Primary studies

With respect to primary studies of the effects of organisational models for provision of health and dental care to children and adolescents in OHC, no studies with low or medium risk of bias were identified. Excluded full-text papers are described with full reference and reason for exclusion in Supplement S2.

3.3 | Excluded studies of interest

Supplement S3 includes a description of studies that did not meet the inclusion and quality criteria overall, but which may still be of interest. There were a few studies of quasi-experimental design which did not meet the inclusion criteria. Other studies of potential interest were cohort studies with pre- and post-measurement, time-series studies without a comparison group and studies for validation and testing of standardised instruments. However, the results of these

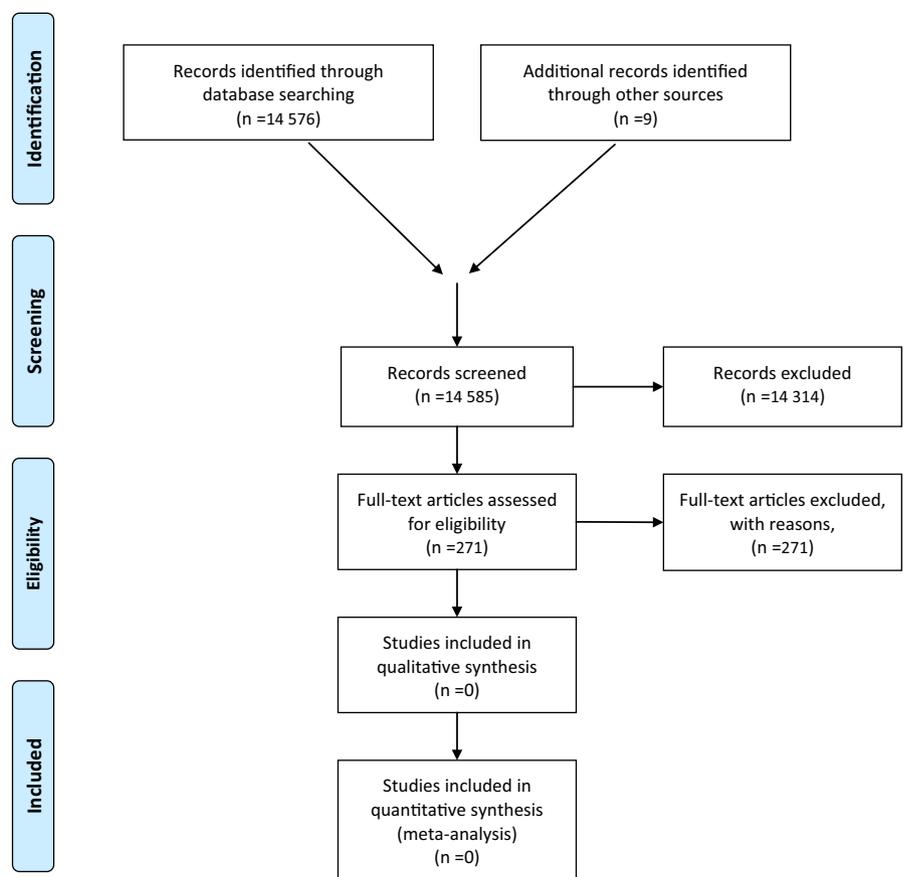


FIGURE 1 Literature review flow chart. Modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2009 version⁹⁰

studies should be interpreted with caution, as the study designs may increase the risk of bias.

4 | DISCUSSION

Of the total of 14 585 studies, 271 were read in full text. Despite the high volume of published papers, critical scrutiny failed to identify any study with low or moderate risk of bias. This result is disconcerting, given that children and adolescents placed in OHC are extremely vulnerable, with high rates of somatic, dental and mental health problems. This has been acknowledged by the scientific community since the 1970s, in literally hundreds of studies from many different countries. Furthermore, these children should be regarded as highly dependent on state initiatives to ensure that they receive adequate health care, on par with other children in the community.

Although Swedish children in OHC are included in the universal health care system, including free preventive child health care and dental health care, several studies have indicated that they are not well served by this system.^{26,27,29,30} International research, summarised in a recent report to the EU-commission, has reported similar findings⁷³. The consequence is that the health care needs of children in OHC are often neglected, and the children are thereby denied their right to the best attainable health.

4.1 | Reasons for high rates of health problems

There are several possible reasons why children in OHC—and subsequently also as adults—have more health problems than their peers.⁷³ These include a history of abuse and neglect, parental neglect of health care needs, older children commonly failing to attend medical and dental appointments, parental mental health problems leading to genetic vulnerability, and poverty and stress leading to early adverse effects on health. Moreover, adverse childhood experiences have a cumulative effect, strongly linked to somatic and mental health problems.^{73,78,79} However, there is also accumulated evidence of negative consequences attributable to a general lack of systematic routines for provision of health services in OHC, over-reliance on carer observations and even of neglect of health issues by child welfare authorities.^{19,26,29,30,80-84} The instability of OHC (multiple placements/changes of residence over time are common) probably contributes significantly to this issue.^{20,81} Not everything can be blamed on the birth parents or on the children themselves.

Since the 1970s, researchers, paediatricians and others have recommended that child welfare and health authorities should develop regulations and models for systematically ensuring comprehensive health care (including preventive and dental health care) to children and adolescents in OHC.⁷³ There are promising initiatives, at national and local levels, but to date, these models have not been subjected to rigorous scientific evaluation.

4.2 | Ethical, social and legal aspects

Ethical, social and legal issues arise in selection of organisational models for provision of health services to children in OHC. The encompassing principle in the Nordic child welfare systems is that children in OHC are entitled to the same standards of health and dental care as other children in the community. The regulations include legal responsibility for society to provide good care for children and adolescents in OHC, whose parents (for various reasons) are unable to meet their legal parental obligations. The legal and ethical values⁸⁵ are best summarised by the credo 'in loco parentis', 'in the place of parents'.⁸⁶⁻⁸⁸ When the state assumes responsibility for non-temporary, 24-hour care of children, the state should meet our expectations of reasonably able parents, including adequate care of the children's health. This issue is, however, complicated by the fact that responsibility for the children's wellbeing is fragmented: several agencies are involved, for example child welfare authorities and health care providers. Thus, the distribution of responsibility may be unclear.

One way to support child welfare authorities in the work of addressing the children's health needs is to implement high quality and well-functioning organisational models, with routines and supporting documents for the daily work of child welfare authorities. To clarify the agencies' respective responsibilities, Swedish legislation was amended in 2017, with more stringent requirements for health care providers to investigate the health and dental care needs of children in out-of-home placements (Lag (2017:209) om hälsoundersökning av barn och unga som vårdas utanför det egna hemmet). The new regulation has not yet been evaluated, and to date has been implemented only sporadically.^{74,89}

A paramount principle of relevance to any organisational model is to avoid inequalities in the provision of health care for children in OHC, compared with other children in the general population, and to compensate for inadequate health care before placement in OHC. These goals require legal clarity and a strong need for systematic procedures and documentation to ensure that these children's health care needs are not addressed randomly or unfairly by the authorities. However, equivalent treatment should not mean that the authorities treat all children according to the same template, without regard to individual needs. The conclusion of this review is that special organisational solutions are necessary to ensure that OHC children receive the health and dental care they need.

Another principle concerns children's rights under the United Nations Convention on the Rights of the Child (CRC). In recent decades, the rights of children with respect to their contact with authorities have been gradually incorporated into legislation in the Nordic countries. The right of children to health care on equal terms is a fundamental component of the Convention. According to Articles 24 and 25, all children have the right to health care. Other key elements of the Convention are the right not to be discriminated against (Article 2), the best interests of the child (Article 3) and the right to be heard (Article 12). The Convention also affirms the aforementioned significant *in loco parentis* principle. In January 2020, the Convention

will be incorporated into Swedish law (Lag [2018:1197] om Förenta nationernas konvention om barnets rättigheter). This will enable Swedish agencies to cite the CRC directly as a basis for their decisions.

4.3 | A hypothetical organisational model

In the HTA-project conducted by the Swedish Agency for Health Technology Assessment and the Assessment of Social Services, a hypothetical organisational model was described and estimated cost calculated.⁷⁴ The model was inspired by the English model and the Mariagerfjord process (see Supplement S4) but adapted to current conditions at local government level in Sweden. The model includes a standardised comprehensive health and dental status check-up by specialist health and dental personnel when the child or young person is placed in OHC; nationally developed, age-specific checklists with supplementary local information to plan the health and dental care measures; and an update twice a year by the child's designated social worker on measures taken to remedy health and dental problems. The resource requirements and costs for this hypothetical organisational model are modest; per child and year estimated costs of SEK 3 500 (approximately € 350). The initial health and dental status check-up when the child is placed would require around 4 hours of a specialist medical officer's time and 1 hour of a specialist dental officer's time, at an estimated total cost of SEK 4 900 (approximately € 490). When ending placement in OHC, there is also need for a specialist dental officer to do a full dental examination including referral to general practitioner at an estimated cost of SEK 2 400 (approximately € 240). The estimate for specialist medical officer is based on a need for the medical officer to go through all available medical records from different health care providers and a comprehensive medical assessment including acquired medical and psychological tests. The cost for the dental specialist is based on the social insurance system's level of reimbursement for a comprehensive dental examination by a specialist. The most expensive item would be setting up the model, which includes training of social workers and collating the information for the national and local checklists, estimated to cost around SEK 5.5 million (approximately € 550 000) during the first year of model implementation.

4.4 | Need for further research

There are several reasons why this systematic review failed to identify studies on effective strategies to health care before, during or after placement in societal out-of-home care. Firstly, there are obvious legal issues. In most countries, medical, dental and social care are regulated by different legislation. This results in health and welfare officers working in isolation, with infrequent communication across the jurisdictions. Sometimes, the confidential nature of health care, which precludes disclosure of information, may hinder or complicate necessary inter-disciplinary collaboration.

The acceptance and adoption of evidence-based medical care have resulted in greater stringency with respect to research methodology and study design. Today, this is a prerequisite for attaining funding,

ethical approval and acceptance of manuscripts for publication. This might be more readily achieved in medicine than in many other scientific fields, because the research conditions are less complex. In order to facilitate important evaluation and identification of significant and effective concepts in social sciences, greater consistency in study designs is advocated, to facilitate comparison of interventions or methods.

There is a fundamental need for rigorous evaluations of current models (see Supplement S4) for systematic assessment of health care needs and provision of health care to children in OHC. Moreover, experience from England has clearly shown that systematic follow-ups of initiatives from legislators, at the national level, are needed if new guidelines and legislation are to be more than 'fancy words'.⁷³

5 | CONCLUSION

This systematic review of the literature failed to disclose any studies of adequate quality. It is therefore not possible to determine the effects of organisational models for providing health and dental care to children and adolescents in out-of-home care. Henceforth, when organisational models are implemented, well-conducted follow-up studies should be undertaken to evaluate their effects. There is also a need for studies that assess the prevalence of physical, dental and mental health problems and oral disease among children entering or already placed in out-of-home care.

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CONFLICT OF INTEREST

In accordance with SBU's regulations, the experts involved in the project have submitted declarations of conflict of interest. These documents are available at SBU's office. SBU has deemed that the declarations confirm that the participants fulfil the requirements of objectivity and impartiality.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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