ORGANISATION OF CHILD AND ADOLESCENT MENTAL HEALTH CARE: STUDY OF THE LITERATURE AND AN INTERNATIONAL OVERVIEW.

SYNTHESIS
ORGANISATION OF CHILD AND ADOLESCENT MENTAL HEALTH CARE: STUDY OF THE LITERATURE AND AN INTERNATIONAL OVERVIEW.

SYNTHESIS

MOMMERENCY GIJS, VAN DEN HEEDE KOEN, VERHAEGHE NICK, SWARTENBROEKX NATHALIE, ANNEMANS LIEVEN, SCHOENTJES ERIC, EYSSEN MARIJKE
SYNTHESIS

1. INTRODUCTION

In the last decades of the previous century, major reforms were introduced in the mental health care (MHC) sector in Western countries, including Belgium. Where adult MHC had previously been characterised by placement in large isolated institutions, a balanced care model gradually came to the forefront: the care offered is delivered as close as possible to the patient's living environment, and only if necessary in an institution. This model also implies the development of a variety of services that enable care to be provided close to home. At the same time it also proved important to ensure a smooth and seamless transition from one service to another.

Mental health problems in children and adolescents are not uncommon. Based on studies that used a validated questionnaire, the WHO (World Health Organization) estimates that the prevalence of mental problems and disorders in children and adolescents in Western countries is about 20%, and approximately 5% are believed to require clinical intervention.

The MHC sector for children and adolescents developed much later than that for adults, and as a result has a different care structure. Nevertheless the reform principles outlined above are also gaining ground in this sector. Moreover, care for children and adolescents often has to take place across the boundaries of the MHC sector. Indeed, support is often offered through, e.g. the GP or paediatrician, and many problems in children and adolescents first come to light outside the care sector, e.g. at school. When discussing MHC for children and adolescents it is therefore also important to involve these so-called “adjacent sectors”: welfare, justice, disability care, education.

2. OBJECTIVE

The purpose of this report is to bring together knowledge on organisational aspects of child and adolescent MHC, and to do so in the light of the context outlined above. The specific therapy content is not taken into consideration. The report consists of two parts:

- a descriptive overview of the literature about:
  - organisational aspects of child and adolescent MHC,
  - financing of child and adolescent MHC;
- an international overview of the organisation of child and adolescent MHC, with:
  - a detailed analysis of child and adolescent MHC in Belgium,
  - a description of the MHC organisation for children and adolescents in 3 other countries.

This report only brings together the available information, it does not formulate any proposals from this for the organisation of care in Belgium. The data from the literature and the examples from other countries do in fact have to be interpreted in light of the specific Belgian context. The Belgian stakeholders will be involved in this interpretation process and in the formulation of reform proposals, the results of which will be presented in a separate report.
3. OVERVIEW OF THE LITERATURE

Peer-review databases were studied for the overview of the literature (see report 2.1), but grey literature was also considered. In addition to a comparative investigation, descriptive studies and qualitative research were included.

3.1. Care Organisation Models

3.1.1. Preliminary methodological notes.

Two types of publications were selected for this topic:

- articles that describe organisational models,
- articles which, using an evaluation process, study whether a specific organisational model has an added value compared to another model or not.

The scope of the research is so broad that it is almost impossible to be comprehensive. The focus is therefore on the most common and main models and those for which a comparative study was conducted.

In the comparative study, only a few aspects of a specific model were generally addressed, so that it is difficult to make a judgment on the model as a whole. In addition, there are numerous methodological limitations. The interventions are complex and cannot be viewed separately from the context in which they are implemented. The majority of publications come from the US, which limits the relevance of their results for Belgium. The interventions described often have numerous facets, and it is not always clear which part exactly makes the difference. In addition, there are other frequently recurring limitations, such as small sample sizes, unclear outcome measurements, etc. For all these reasons this overview is purely descriptive and narrative.

Finally, we should note that the majority of the models described were for the subgroup of children and adolescents with severe emotional and/or behavioural problems.

The two main models that emerge from the literature are the WHO model and the Systems of care model. Both are presented in general terms and need to be further elaborated by the country or region that seeks to implement child and adolescent MHC.

3.1.2. The WHO model

The WHO strongly recommends the elaboration of a child and adolescent MHC policy at the national level and to translate this into a clear plan. In 2004 it first published a report describing the countries worldwide where a policy and policy plan for child and adolescent MHC was in effect. A limitation of this report is the low level of participation in the surveyed countries. In Europe 96% of the participating countries (including Belgium) had a specific policy for child and adolescent MHC available. However, a national action plan with general and specific lines of policy (“who does what by when”) was only available in 67% of those countries. In the majority of countries it was also not possible to clearly define the available budget. Budgets often proved to be temporary or to come from vulnerable sources of funding, rather than based on stable government budgets. The budget also proved significantly lower than the budget for adult MHS.\(^1\)

As a result of this research, the WHO published a guideline in 2005, that gives step-by-step advice on how a policy and policy plans could be drawn up and disseminated in this field.\(^2\) In the same publication it also describes a model for the organisation of child and adolescent MHC (Figure 1). The model is neither all-inclusive (e.g. it does not include all the adjacent sectors) nor is it scientifically validated. It is nevertheless often referred to internationally.
3.1.3. Systems of care

3.1.3.1. Background and definition

A great deal of literature was found on the Systems of care model. Developed 25 years ago in the US, the model was a reaction to the then “medicalised”, fragmented and hospital-bound child psychiatry. The Systems of care model is primarily intended for children and adolescents with severe behavioural or emotional disorders, and also for their families. Some authors also use the concept for the entire group of children and adolescents with MHC needs.

Systems of care is in essence not a ready-made organisational model, but a framework or a philosophy intended to offer guidance in the development of a care system. There are different definitions; the definition by Stroul (2010) (see text box 1) is one of the most recent.3

Text box 1: Definition of Systems of care

“a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organised into a coordinated network, builds meaningful partnerships with families and youth and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.”

According to the designers of the model, the underlying principles and values of the Systems of care are at least equally important as the definition.3 The basic principles are:

- access to a broad spectrum of services,
- treatments tailored to the needs of the child and family,
- treatment in the least restrictive environment possible, taking account of the nature of the behavioural problems, and using the possibilities for community-based support close to or at home,
- full participation of families as partners,
- care that is coordinated amongst the various care providers,
- use of e.g. case management for coordination of care,
- early detection and intervention,
- smooth transition from youth to adult care
- effective defence of interests by patient groups,
- non-discriminating service that takes account of cultural differences.

3.1.3.2. Implementation

The implementation of Systems of care is a multifaceted process that involves different levels:

- the state level: adjustments in policy, funding methods, development of workforce, etc.;
- the local care organisation level: improvements in planning, managing and evaluating the provision of care; providing the necessary infrastructure;
the actual service delivery level: changes whereby a broad range of effective types of care can be offered.

In practice, many different forms of care can contribute to the implementation of the Systems of care model on the last two levels. Every country or every community that wants to implement Systems of care must tackle the basic principles themselves and from there determine which policy changes are required, and what forms of care are most suitable for implementation in the local context.

3.1.3.3. Scientific evidence

In the US, large-scale studies were set up in the '90s, the Fort-Bragg and the Stark County studies\textsuperscript{4, 5}, which aimed to evaluate the Systems of care model. These studies are of good quality with a low to moderate risk of bias.

In an experimental group, changes were implemented such as different types of funding, a broader range of available services with both residential and outpatient care, and the provision of care coordination; this was compared with a control group.

Positive effects were recorded in the experimental group, such as better access to care, better care coordination, and a higher level of patient satisfaction. However, the clinical and functional outcome parameters did not improve. The conclusion was drawn that reforms should not only tackle the care organisation but that also the actual content of the care should be improved if an improvement of the clinical or functional conditions is to be achieved.

3.1.4. Models at the local care organisation level or the service delivery level

Comparative research was also found for a few other models in the overview of the literature. These relate to models at the local care organisation level, or models at the service delivery level. However, in practice the three levels mentioned are often entwined: models that aim at the organisation of care at the level of the individual patient, e.g. wraparound (see below), also quite commonly require an adjustment of the care structure at the local level and measures at the national/regional level.

Some of the identified models, e.g. multi-system therapy (see below), not only relate to the organisation of care but also embody a vision of the content of the therapeutic action, and then also refer to specific therapeutic models. On the other hand, the choice of a specific therapeutic model often also has an influence on the organisational aspects, such as the composition of the team, the frequency and duration of the contacts with the care provider, etc. As already mentioned, the study of the therapeutic models does not fall within the scope of this study.

3.1.4.1. Models for community-based intensive care

For each of the models defined below, individual studies often show positive results for one or more of the measured parameters. The validity of these results is limited due to numerous methodological problems. Systematic reviews of good quality that studied these forms of care therefore concluded that no conclusions can be drawn, or, at best, that the results are promising but need to be supplemented with additional research. The majority of these studies were conducted in the US.

Case management: a mechanism to link and coordinate different components of a care system so as to create a programme that fully meets the care requirements of an individual client. Subtypes include e.g. intensive case-management, assertive outreach (see report 3.6.1).

Wraparound: planning and coordinating care, starting from the individual needs of the child and his family. This typically relates to children and youths with complex care needs, in which a team “wraps” the care around the child and the family. The concept of Wraparound is supported by a set of values that fit closely with the Systems of care model, and it is often considered the most concrete elaboration of the Systems of care model.

Therapeutic foster care: care with foster parents that are trained and supported so that they can tackle the behavioural problems of their foster child, and aimed at foster children who would otherwise end up in a more restrictive environment due to their behaviour, e.g. in an institution.

Multi-system therapy: a multidimensional, short-term, intensive treatment at home or in the community near home, for children and youths who run the risk of being placed out of the home due to severe behavioural problems. It was originally developed for young delinquents. In Multi-system therapy, behaviour is seen as the result of the interaction between
individuals and their social environment. In this therapy not only the adolescent but also family, friends, school and community are involved. Multi-system therapy is covered by patent rights.

3.1.4.2. Models for mental health care in schools

There is evidence of moderate quality that the provision of preventive programmes or early intervention in schools may have a positive effect on the prevention of anxiety and the development of self-confidence. There are multiple models for the way in which mental health care could be organised in school; many schools have implemented components of one or more of these models. For details see report 3.6.3.

3.2. Financing Models

The literature search yielded very few results: 4 reviews about funding in mental health care, without any specific focus on children and youth; and 10 primary studies on funding of child and adolescent MHC, of which 9 were carried out in the US. These results are therefore of limited relevance to Belgium. Numerous methodological limitations also make it difficult to draw far-reaching conclusions. For these reasons, only a simple descriptive, narrative overview can be given of the literature found.

It is clear from research that payment per service may constitute a barrier to multidisciplinary work and may increase the administrative burden. On the other hand, paying fixed sums per patient (“capitation”) results in inadequate care for patients who need numerous services. Integration on a financial level may be desirable to promote care integration, but there has been exceptionally little research in this area.

Based on past international experience, the WHO warns in one of its reports against the abrupt transfer of financial means from the hospital sector to the outpatient sector. This kind of transfer is only advisable if it is sufficiently clear that the outpatient sector can genuinely offer the necessary support to people who were previously supported in the hospital sector. As long as this is not adequately guaranteed, dual funding should be provided. The WHO also warns against the risks connected to "pooling" or merging budgets from different sectors, such as mental health care and welfare. It is important that the budget for mental healthcare remains earmarked as such, otherwise it may disappear unnoticed into the overall budget and be used for other purposes.

4. INTERNATIONAL OVERVIEW

4.1. Method

Due to time and resource constraints, the choice was made to limit this part to Belgium, the Netherlands, Canada (British Columbia) and England. The selection of these other countries started from a long-list to which a number of selection criteria were subsequently applied (see report 2.2 and Appendix 2). There are, however, numerous other interesting organisational forms, as illustrated in a brief description of a recent experiment in France (see report 6.5).

The information for each country comes from peer-reviewed literature and grey literature (policy statements, descriptive documents and reports ...). In addition, local experts were contacted for information. No new information was added after July 1st 2011.

Finally, four to five representative persons for the Netherlands, Canada (British Columbia) and England were contacted: policymakers, care providers, scientists, and patients. They were asked to formulate their critical thoughts on the system in their country. A response was received from 1 to 2 representatives of each country. This exercise was not done for Belgium as this aspect will be dealt with in the second part of the study, in which work will be carried out with the stakeholders around possible future scenarios.

An overview in a table format is given in the report for the 4 countries studied (Table 6.1 in paragraph 6.6). Below we give a few striking points for each country, without trying to be comprehensive. We refer the reader to the text and the key-points at the end of chapter 5, 6.2, 6.3, 6.4 in the report, for a systematic description of the health care sector and the adjacent sectors and the way in which these sectors work together.

The reforms in the countries described always start from the context in that country for health care or for the adjacent sectors, and can therefore not simply be adopted by other countries. It is also not easy to compare the countries, the more so because there is hardly any information on what the
results of the implemented policy mean to the care organisation, care processes and the patient.

4.2. Belgium

In Belgium the authority for MHC (as for general health care) is divided across the federal government on the one hand and the communities and regions on the other hand. In recent years numerous joint initiatives have been taken by both policy levels, such as projects to promote and evaluate care networks and care circuits.

There are numerous services that offer primary MHC care. Primary MHC care for children and adolescents includes services like GPs; Kind&Gezin/ L’Office de la naissance et de l’enfance (ONE); Centra voor leerlingen begeleiding (CLB)/ centres psycho médicaux sociaux (CPMS). Unlike other countries, the role of these primary care providers has not been formally recognised nor supported by policy.

As regards specialised child and adolescent MHC, there is a broad range of care with a variety of funding mechanisms. It is, however, not always clear to what extent certain forms of service overlap or if there are any gaps in the system.

The system provides for a number of structural ways to promote cooperation within the sector or with other sectors, e.g. specific funding for a child psychiatrist who consults other care providers, or support for care providers from other sectors by staff from the Centres of Mental Healthcare (Centra voor Geestelijke Gezondheidszorg/ Services de santé mentale; CGG/SSM). However, little research is available on whether this produces the desired effect and where additional measures are required.

To assure a more specific offer of care, a number of projects were launched in the last decade for a number of target groups, e.g. for youths with MHC needs who have come into contact with the courts (FOR-K). In these projects, the various types of care available to these patients (residential, crisis care, outpatient support) are usually coordinated. However, there is as yet no structurally anchored funding.

In Flanders, work has been done for some years on the start-up of Integrated Youth Care. A common policy is implemented for all sectors involved in helping children and adolescents and that fall within the policy domain of Welfare, Health and the Family. This concerns welfare, care for the disabled, education, preventive care services and outpatient centres for mental health care. The joint policy implies a single central management, the creation of local networks but also the organisation of a central portal to intensive youth care services. In this way, it is aimed to achieve better care integration and more efficient assistance. However, residential MHC treatment, under the responsibility of the federal government, falls outside of the scope of this decree.

For more information, see the report in chapter 5; for more information about emergency psychiatric help for children and adolescents, see KCE report 135.

On 9 June 2011 a report was published by the National Council for Hospital Supplies/ Nationale Raad voor Ziekenhuisvoorzieningen/ Conseil National des Etablissements Hospitaliers. This report presents the current problems and the future needs described in the child and adolescent MHC sector in Belgium. The report is based on a broad consultation of experts working in this field, and approaches the subject discussed in this document from another angle.

4.3. The Netherlands

To enable more efficient care coordination amongst a number of sectors involved in the welfare of children and adolescents, the Youth Care Agency was established in 2005. This aims at being a common portal for child and adolescent mental health care services, youth social work, and care for children and adolescents with a mild mental retardation. These policy domains all fall within the competence of the Minister for Health, Welfare and Sport. The Youth Care Agency is responsible for directing all reports to the appropriate service, either within mental health care, within youth welfare or within other fields like justice, disability care, or special education. Referral to specialised mental health care for children and youth also remains possible through GPs, psychologists or medical specialists.

Currently this system of a “common portal” is again the subject of strong debate. A recent evaluation revealed that the system, in particular for referrals within the welfare sector, was considered a positive experience. However, numerous obstacles came to light, e.g. fundamental differences between the health and welfare system as regards basic funding principles (either according to market principles or fully subsidised). In practice, this
results in a number of practical barriers. The majority of referrals to specialised mental health services in 2009 was made by physicians and not by the Youth Care Agency. Referrals to disability care or education should also be further harmonised with the existing referral system within these sectors; in fact a dual referral system has been created in these sectors.

The solution currently put forward is to transfer mental health care for children and youth entirely to the welfare sector, and to ensure uniform financing of both systems via the municipalities. However, these plans are strongly opposed by the mental health care sector, which maintains, among other things, that a permanent link with the health care system is essential.

Recent data also indicated that only a limited number of the children and youths require help from different sectors, so that the question is raised whether it would not be better to find a solution for this group rather than reforming the entire system. For more information, see report 6.2.

Another recent development concerns the increasing demand for specialised assistance for children and adolescents, especially in MHC and youth work. To be able to offer an answer to this, the Netherlands has in recent years placed particular emphasis on prevention and primary health care. Thus, for instance, municipal centres, the Centrum voor Jeugd en Gezin (CJG), have been set up which are responsible for preventive actions but also for primary care advice and help with all kinds of questions relating to health, education, mental health and social problems. Work has also been done on improving cooperation between the school, primary care services and the Youth Care Agency.

4.4. Canada

In Canada the child and adolescent MHC sector is in full expansion. In 2010 the federal government of Canada launched a general framework for developing a child and adolescent MHC policy within the 13 provinces and territories, which have great autonomy in terms of health care organisation. Already in 2003, British Columbia (BC) was the first to draft its own plan. This plan outlined the general operating principles such as the importance of evidence-based treatment and outcome monitoring, of cooperation across the sectors, etc. Doubling of existing funding was provided over 5 years. A significant part of this was invested in prevention.

BC allocates a central role to outpatient MHC in specialised centres for the care of children and adolescents with MHC needs. These multidisciplinary centres exclusively treat children and adolescents. A referral from one of these centres is required to be admitted to the highly specialised tertiary centre. Emergency admission takes place via general hospitals. For more information, see report 6.3.

4.5. England

The “Children’s trusts” were launched in England in 2004 to allow better cooperation and more integrated operations amongst the various services for children and youth. Local agencies met in the Children’s trust to plan and organise all the services required for children and adolescents in the region. Health care, mental health care, welfare, justice, disability care and education were included. To realise this, experiments were made in bringing together budgets primarily of health care and welfare; however, little exact information is available on these processes. It should be noted that England has a long tradition of health care and welfare organisation at the local level. For health care, this is realised under the central direction from the English NHS (National Health Service).

The new government that took office in May 2010, again abolished the Children’s trusts. The reasons for this are not quite clear. At the time of writing this report, it was still unclear what the new organisation and funding structure for mental health care for children and adolescents would actually look like.

In England there are already a number of practical aids designed to support cooperation amongst the various services and sectors, such as a standard dossier for child and adolescent MHC to exchange information, and a clinical evaluation tool for primary health care providers. In addition, the use of standard measurement tools to measure clinical results achieved and to collect data is already highly developed. Finally, England also has standards for the training of staff who work with or come into contact with children or adolescents with MHC problems. For more information, see report 6.4.
5. CONCLUSION

The importance of a national/regional policy for child and adolescent MHC, made concrete in a clear plan, has been recognised for some time. Nevertheless, the literature on organisational models within child and adolescent MHC offers little guidance to policymakers. The two main models found in the literature only give main policy lines of a general nature. Each country or community that intends to implement one of these models, must themselves work with the basic principles and develop a further policy from there.

Furthermore, the scientific studies in this field are of limited quality and many policy issues are not or inadequately researched. It has, however, been shown that, if attention is paid to aspects of care organisation according to the Systems of care, care can be made more accessible and can proceed in a more coordinated way, resulting in greater patient satisfaction. This does not, however, imply that the clinical and functional outcomes are better. It may be concluded from this that the government should not only stimulate better care organisation and coordination. It must also not lose sight of the importance of the content of the therapy and should also develop, disseminate and offer effective therapeutic concepts.

It has also been shown that, for the limited subfield of anxiety disorders, organising preventive actions and early treatment through the schools is effective. This confirms that the approach to mental health care problems in children and adolescents cannot be restricted to the health care sector, but that one should also have the courage to look for solutions within other sectors.

In the countries studied, the reforms are based on theoretical frameworks based on major ethical principles and values; these principles and values overlap significantly between the different countries. However, in the practical implementation of this conceptual framework, numerous difficulties are experienced and in some cases the predefined objectives are not achieved. There is usually little hard data on the actual result of the reforms implemented. Perhaps a positive result is only possible if the clinical, organisational and financial aspects are addressed simultaneously, clearly bearing in mind the unique nature of each of the sectors involved.

The literature and the international overview therefore only offers us a limited basis in the search for a better organisational structure for child and adolescent MHC. In the next phase of this study this will be considered with the stakeholders in the field. These results will be published separately.

6. REFERENCES

Colophon

Title: Organisation of child and adolescent mental health care: study of the literature and an international overview

Authors: Mommerency Gijs (UZGent), Van den Heede Koen (KCE), Verhaeghe Nick (UGent), Swartenbroekx Nathalie (KCE), Annemans Lieven (UGent), Schoentjes Eric (UZGent), Eyssen Marijke (KCE)

External Experts: Bontemps Christiane (IWSM), Boydens Joël (CM), Braet Caroline (UGent), Danckaerts Marina (UZLeuven), De Becker Emmanuel (UCLouvain), De Bock Paul (FOD Volksgezondheid), Deboutte Dirk (Universiteit Antwerpen), De Cock Paul (UZLeuven), De Lepeleire Jan (KULeuven), Delussu Rosanna (Conseil de l’Enseignement des Communes et des Provinces), De Vleeschouwer Didier (Plate-forme Namuroise de Concertation en Santé mentale), Ghariani Sophie (CNWL), Lampo Annik (UZ VUB), Lebrun Thierry (Les Amis de la Petite Maison - ACIS asbl), Petry Katja (KULeuven), Put Johan (KULeuven), Simoens Steven (KULeuven), Van Speybroeck Jan (VVGG)

Acknowledgements: Brekelmans C (GGZNederland, NL), Hewson L (Bradford Counseling Service, UK), Kelvin R (Department of Health, UK), Kingsbury S (CAMHS Hertfordshire Partnership Trust, UK), Kutzer S (Dahlsouzie University, Ca), Leys M (VUB, Be), Menting J (Yulius Mental Health, NL), Minotte P (IWSM, Be), Rees D (Independent Development Consultant, UK), Rietveld AA (Accare University Centre for child and adolescent psychiatry, NL), Van Nuffel R (VUGG, Be), Waddell C (Simon Fraser University, Ca), Wijnands Y (Ministry of Health, Wellbeing and Sports, NL), York A (South West London & St George's Mental Health NHS Trust, UK), Garcin, V. (EPSM Lille-Métropole, FR)

External Validators: Resch Franz (Universitätsklinikum Heidelberg), Tremmery Bie (UPC K.U.Leuven), Delvenne Véronique (Hôpital Universitaire des Enfants Reine Fabiola)

Conflict of interest: F. Resch (Universitätsklinikum Heidelberg) declared that he had received a fee from a pharmaceutic company for an oral communication (Février 2011)

Layout: Ine Verhulst, Sophie Vaes

Disclaimer:
- The external experts were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.
- Subsequently, a (final) version was submitted to the validators. The validation of the report results from a consensus or a voting process between the validators. The validators did not co-author the scientific report and did not necessarily all three agree with its content.
- Finally, this report has been approved by common assent by the Executive Board.
- Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE
Publication date: November 29th 2011
Domain: Health Services Research (HSR)
MeSH: Mental Health Services; Child; Adolescent; Organizational policy; Health services research
NLM Classification: WM 30
Language: English
Format: Adobe® PDF™ (A4)
Legal depot: D/2011/10.273/81

Copyright: KCE reports are published under a "by/nc/nd" Creative Commons Licence
http://kce.fgov.be/content/about-copyrights-for-kce-reports.


This document is available on the website of the Belgian Health Care Knowledge Centre