KCE REPORT 175 B

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

SOINS DE SANTÉ MENTALE POUR ENFANTS ET ADOLESCENTS: DÉVELOPPEMENT D'UN SCÉNARIO DE GOUVERNANCE





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HEALTH SERVICES RESEARCH

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Conflits d'intérêt:	Tous les experts consultés dans ce rapport ont été sélectionnés pour leur implication dans le secteur des soins de santé mentale pour enfants et adolescents. Par conséquent, ils peuvent avoir des intérêts potentiels de différentes natures liés au sujet principal du rapport
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PRÉFACE

Quand quelque chose arrive à des enfants, cela nous touche profondément. La société se doit de veiller à prévenir ou à soigner de façon adéquate la maladie et la souffrance des enfants, encore plus que celles des adultes. Pour les soins de santé mentale, c'est encore plus vrai parce que le développement futur de l'enfant et toute la suite de sa vie peuvent en être affectés. De plus, contrairement aux maladies somatiques, un problème mental percole pratiquement dans tous les domaines de la vie de l'enfant. Ce qui signifie que de nombreux acteurs y sont confrontés : tout d'abord les membres de la famille, les amis et l'école, mais cela peut aussi aller beaucoup plus loin, jusqu'aux services de police ou de la justice.

C'est ainsi qu'au fil des ans, on a vu apparaître nombre d'initiatives, y compris en dehors ou à côté de la psychiatrie infantile ou de la jeunesse. Mais malgré la multitude d'initiatives assurément souvent très valables et malgré l'investissement compétent et généreux de tant de personnes, on se plaint de longues filles d'attente et il règne un profond malaise dans le secteur. S'il y a bien une idée sur laquelle tout le monde est d'accord, c'est que cela ne peut pas continuer ainsi.

Dans le présent rapport nous tentons de jeter un peu de lumière sur cette problématique complexe et multidimensionnelle, et nous explorons des pistes pour sortir de l'impasse. Il ne s'agit pas de la première initiative en ce sens, ce qui indique dès l'abord qu'il n'y a sans doute pas de solution miracle et rapide au problème. Nous n'avons effectivement pas trouvé de *'magic bullets',* mais nous dégageons néanmoins un certain nombre de recommandations destinées à enregistrer des progrès aux niveaux micro, meso et macro. Nous avons impliqué activement tous les stakeholders dans le processus de réflexion, un processus qui est parti de l'analyse du système dans toute sa complexité, au delà des structures et des groupes d'intérêt particuliers.

Il faut maintenant traduire les recommandations en projets et en actions concrètes. On le doit bien à tous ceux qui ont consacré de leur temps et partagé leurs idées avec les chercheurs ; mais on le doit aussi et surtout aux enfants et aux adolescents qui ont non seulement besoin mais aussi le droit à une aide experte de la part de notre société d'adultes.

Jean-Pierre CLOSON
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RÉSUMÉ

INTRODUCTION

En 2005, l'Organisation mondiale de la Santé (OMS) lança un appel pour une action nationale dans le domaine des services de santé mentale pour les enfants et les adolescents (Child and Adolescent Mental Health Services - CAMHS). Cet appel à une démarche ciblée est motivé, d'une part, par le taux de prévalence élevé des problèmes de santé mentale au sein de ce groupe et, d'autre part, par leur impact potentiel sur le développement et sur le bien-être et le fonctionnement à l'âge adulte. L'OMS recommande de ne pas seulement inclure la pédopsychiatrie classique dans l'action nationale mais aussi ce qu'on appelle les "secteurs connexes" comme l'action sociale, la justice, les soins aux personnes handicapées et l'enseignement.

Néanmoins, la Belgique ne possède pas de stratégie clairement définie en matière de CAMHS. Comme dans d'autres pays occidentaux, les réformes passées se sont essentiellement focalisées sur le secteur de la santé mentale chez l'adulte, qui se caractérisait traditionnellement par de grandes institutions isolées. Depuis le début du 21ième siècle, le modèle de « soins équilibrés » (*balanced care*) gagne progressivement en influence dans ce secteur. Le modèle en question signifie que les soins sont proposés et fournis le plus près possible du milieu de vie du patient et ne sont dispensés en institution que lorsque cela est nécessaire.

Le secteur des CAMHS s'est développé nettement plus tard et n'a pas de tradition de grandes institutions hospitalières isolées. En conséquence, une approche différente pourrait s'avérer nécessaire.

OBJECTIF

Le KCE a été mandaté pour réaliser une étude visant à apporter des éléments pour une réforme du système des CAMHS. L'étude comprend deux volets.

Le premier volet a évalué les connaissances scientifiques existantes à propos de l'organisation des CAMHS en procédant à une étude narrative de la littérature de même qu'à une analyse des politiques sur les CAMHS dans quatre pays.

L'objectif du second volet, sur lequel porte le présent rapport, consiste à mettre en place un processus participatif visant à **profiler un futur système belge en matière de CAMHS.**

METHODES

La démarche que nous avons adoptée s'inspire de la « Soft Systems Methodology ». Elle utilise un **processus participatif** pour solliciter la contribution des parties prenantes. Au total, 66 parties prenantes ont participé à un ou plusieurs événements (entretiens, ateliers et tables de discussion). Leur apport a été complété avec **des informations recueillies dans la littérature et des documents existants** en se fondant sur les preuves (limitées) rassemblées dans le cadre du premier volet de cette étude, sur d'autres études connexes du KCE et sur les éclairages de la méthodologie de la pensée systémique. En outre, un récent rapport du Conseil National des Etablissements Hospitaliers (CNEH) présente une analyse d'expert des problèmes réels et des suggestions relatives à l'orientation future du secteur des CAMHS en Belgique. Le document en question nous a énormément aidés dans notre étude et nos conclusions. Nos recommandations seront, le cas échéant, articulées avec son contenu.

Les résultats du processus participatif et les informations des documents existants ont tous deux été utilisés pour procéder à une **analyse diagnostique** du système des CAMHS existant et identifier des **éléments de solution** pour un futur système qui soit plus performant.

Deux ensembles de résultats ont été créés en se fondant sur ces éléments de diagnostic et de solution :

1. La **définition source** (objectif) et le **modèle d'activité** (ou modèle conceptuel des activités requises), qui déterminent le profil idéal du futur système des CAMHS, mais sans en préciser déjà les délimitations, le statut légal, les ressources, etc.
2. Un ensemble de **recommandations stratégiques,** basé sur une comparaison entre le système des CAMHS belge actuel (c.-à-d. une **cartographie des parties prenantes**) et ce système idéalisé, afin d'identifier les chevauchements et l'écart entre les deux (c.-à-d. une **gap analysis**).

Les recommandations stratégiques brossent à gros traits le cadre qui devra être rendu opérationnel par les décideurs, les gestionnaires et les professionnels de la santé.

L'étude n'aborde pas concrètement la gamme d'initiatives spécifiques qui devraient être entreprises pour mener à bien la réforme.

RESULTATS

Blocage du système des CAMHS

- Un vaste consensus s'est dégagé parmi les parties prenantes quant à la situation problématique que connaît le secteur des CAMHS. **Plusieurs domaines problématiques** ont été épinglés, notamment de longues listes d'attente, une demande sans cesse croissante, l'absence d'une vision globale claire et d'un cadre d'évaluation transparent. Les problèmes sont clairement **interconnectés** et le système souffre de fragmentation, d'inefficacité et de soins sous-optimaux.
- La nécessité d'un changement a été abondamment débattue par le passé et est bien reconnue par le secteur. Tandis que de multiples **initiatives locales novatrices issues du terrain même (bottom-up**) **ont vu le jour** ces dernières années, le système de CAMHS **dans son ensemble n'a pas su s'adapter.** Ces échecs ont suscité une méfiance entre acteurs et secteurs, de même qu'une incrédulité par rapport à la volonté de changement d'autrui. Cela étant, les parties prenantes ont exprimé une vive **résistance à toute formalisation et contrôle de type 'top-down**'. Par conséquent, une dualité existe entre le choix prononcé des parties prenantes pour une approche bottom-up et la difficulté de mettre en place des pratiques d'organisation et de gestion performantes pour développer la collaboration inter-agences.
- Tous ces éléments réunis nous amènent à la conclusion que le système des CAMHS se trouve confronté à un problème pernicieux qui entraîne une situation de blocage ('lock-in'). Il est manifeste que des **mesures rapides à court terme ne résoudront pas le problème.**

Objectif et activités requises d'un futur système des CAMHS

La définition source résultant d'une analyse des éléments de diagnostic et de solution dépeint un futur système idéalisé comme suit :

> "Le système des CAMHS est une gamme de services guidés par des considérations éthiques, s'appuyant sur des professionnels et fondés sur des preuves, destinés aux enfants et adolescents souffrant de ou risquant d'être confrontés à des troubles de santé mentale, et à leur entourage. Ces services sont dispensés de façon coordonnée, personnalisée, adéquate par rapport au stade de développement du bénéficiaire et culturellement compétente, dans l'environnement à la fois le moins restrictif possible, cliniquement adéquat et le mieux adapté aux besoins de l'enfant. Son but est d'aider ces jeunes à atteindre un mieux-être et accroître leur potentiel de développement à la maison, à l'école, au sein de la collectivité et tout au long de leur vie."

Le modèle d'activité montre, de manière générique, les 35 activités qui doivent être menées à bien pour atteindre l'objectif du système, regroupées dans 9 modules fonctionnels :

- Planifier, dispenser et coordonner les soins[a];
- Gérer l'accès aux soins et l'entrée dans le système de soins ;
- Fournir des services d'intervention en cas de crise/d'urgence ;
- Développer et soutenir la gamme de services ;
- Assister les familles, les autres dispensateurs de soins ainsi que les jeunes en tant que partenaires de soins ;
- Organiser des activités de prévention et de développement des aptitudes relationnelles de la vie courante;
- Mener à bien des activités d' "identification/repérage" précoce ;
- Développer et affiner le modèle de soins ;
- Gestion du système et amélioration de la qualité.

[a] Le terme "soins" ici et dans l'ensemble du rapport doit s'entendre dans son sens large et pas uniquement de "soins médicaux".

Le modèle d'activité constitue un vecteur de soutien de **trois transformations fondamentales**: au niveau de la famille et de l'enfant, le système des CAMHS doit garantir une atténuation de la souffrance de l'enfant ; au niveau des services, il doit soutenir une meilleure coordination; au niveau politique, il doit assurer une capacité d'adaptation et un respect des valeurs fondamentales. Il reflète la **spécificité du modèle de soins à systèmes multiples** et coordonnés qui est envisagé par la présente étude.

Le modèle d'activité étant **générique**, il permet d'adopter des approches différentes lors de son opérationnalisation.

Du modèle CAMHS idéalisé vers des recommandations stratégiques

La comparaison entre le système de CAMHS idéalisé et la réalité (c.à.d. la **cartographie des parties prenantes**) a mis en évidence non seulement les écarts et les chevauchements. Une fois de plus, cette comparaison a illustré la **complexité opérationnelle et réglementaire de même que la multidimensionnalité** du système des CAMHS, mais également le **potentiel pour de nombreux acteurs de contribuer aux diverses activités qui font que le système des CAMHS fonctionne**.

Sur la base des éléments de solution qui sont ressortis des rencontres des parties prenantes de même que de la littérature et des documents existants (rapports du KCE; recommandations du CNEH), dix recommandations ont été avancées pour soutenir une transition du système actuel, fragmenté et cloisonné, vers une provision de soins et d'assistance efficace, coordonnée et guidée par des considérations éthiques, qui franchissent les frontières des secteurs et des programmes :

- Les recommandations 1 à 4 ont pour vocation, conjointement, **d'organiser les exigences demandées aux rares et onéreux services spécialisés de santé mentale** pour les enfants et les adolescents. Le but est de faire en sorte que les jeunes reçoivent des soins adéquats dans l'environnement à la fois le moins restrictif et le mieux adapté possible. On attend d'une telle approche qu'elle aboutisse à un recours plus avisé aux soins spécialisés et aux infrastructures résidentielles. Les recommandations veulent atteindre cet objectif via la *prévention*, *l'émancipation (empowerment)* des

utilisateurs et de leur entourage (familles), *un filtrage adéquat* au niveau des soins de première ligne et en renforçant la capacité du système à gérer les *situations de crise liées à la santé mentale.*

- Les recommandations 5 et 6 se concentrent sur un **renforcement de la gamme de services offerte par les professionnels de la santé mentale, notamment s'agissant des soins aux enfants souffrant de problèmes de santé mentale graves, complexes et multiples**. Ces situations complexes peuvent ou pas être associées à un comportement violent ou à des barrières culturelles. Les recommandations veulent remédier aux défaillances de responsabilité (passer 'le problème' à quelqu'un d'autre) lors de la prise en charge de ces jeunes, en *renforçant une approche souple et assertive* pour dispenser des soins à ces enfants dans leur milieu de vie et en *améliorant les compétentes culturelles* des dispensateurs de soins.
- Les recommandations 7 à 9 ciblent un **renforcement de la capacité d'adaptation et de la guidance éthique dans le cadre du futur système des CAMHS**. Elles entendent concrétiser cet objectif en s'assurant que les acteurs du système, y compris les représentants des enfants et de leurs familles (entourage), participent à des forums intersectoriels afin de stimuler des partenariats sur une base continue. Elles proposent que toutes les parties prenantes s'engagent à développer une *vision partagée* et une *charte éthique* pour le système des CAMHS au sens large. Elles préconisent également de déployer des efforts continus pour *mieux comprendre les besoins et la provision de services de soins de santé mentale.* Enfin, une recommandation concerne les *méthodes d'évaluation* qui renforcent le professionalisme, la qualité et la multidisciplinarité.
- La recommandation 10 propose des **démarches à entreprendre par la suite.**
- Un projet du texte de ces recommandations a été présenté aux parties prenantes à l'occasion d'un atelier de consolidation.

CONCLUSION

Ce projet de recherche participative a donné aux parties prenantes l'opportunité de réfléchir à l'orientation que devrait prendre une réforme du système des CAMHS.

Une analyse diagnostique a révélé que le système des CAMHS se trouve aux prises avec un **ensemble de problèmes interdépendants,** le principal écueil se situant au niveau de la fragmentation et du cloisonnement extrêmes entre les organisations, secteurs et professions. Le coût d'une telle fragmentation est considérable, tant en termes de souffrance humaine que de gaspillage de ressources. Les parties prenantes reconnaissent cette situation.

Au cours de la dernière décennie, plusieurs initiatives ont été entreprises. Néanmoins, des innovations isolées au niveau des services, quoique bien intentionnées et magistralement mises en œuvre, peuvent risquer à un certain stade d'accroître encore la fragmentation du système. De toute évidence, de telles démarches n'ont pas été en mesure de renforcer la capacité d'adaptation du système dans son ensemble. Les échecs du passé ont suscité une méfiance entre les acteurs et les secteurs.

Les parties prenantes ont affiché une vive résistance par rapport à une formalisation et à un contrôle de type "top-down". Avec pour résultat que les professionnels se rendent compte qu'une manière de travailler en plus étroite collaboration et en réseau est indispensable, mais qu'ils n'accordent que peu de confiance à une officialisation de ces réseaux et à la création de nouvelles fonctions, notamment celles de gestionnaires et coordonnateurs de réseau.

L'ensemble des considérations qui précèdent mènent à une situation de blocage pour laquelle on ne peut escompter de solution rapide. Le **processus de changement sera très probablement de longue haleine** et la présente étude ne constitue qu'un petit pas dans ce cheminement.

Par opposition aux solutions fragmentaires ou de type "top-down", qui sont souvent inspirées de manière disproportionnée par les groupements d'intérêt, la présente recherche met l'accent sur la nécessité d'apporter des **« changements au niveau du système »** afin de soutenir les modifications en termes de provision de services. En nous inspirant des enseignements tirés de "l'innovation des systèmes" et de "la gestion de la

transition", nous mettons en garde contre une perception qui y verrait les manifestations d'une théorie de changement linéaire, comme quoi il faudrait: d'abord améliorer les systèmes, ensuite les services et enfin les résultats cliniques.

Certes, des changements au niveau du système sont vitaux pour soutenir la transition vers un système de CAMHS plus performant. D'autre part, il est aussi important de continuer à encourager une expérimentation au niveau local et à contribuer à la concrétisation de réussites, en particulier lorsqu'elles sont le fruit de partenariats intersectoriels ou intra-sectoriels. Le savoir et le capital relationnel engrangés grâce à de telles collaborations constituent le substrat pour une transformation à l'échelle de l'ensemble du système. Les plateformes cross-sectorielles de gestion et de responsabilisation représentent un point nodal au niveau duquel ces deux dynamiques peuvent s'unir et se renforcer mutuellement par le truchement de plans stratégiques, de conventions inter-agences, de propositions de loi, d'accords de financement, d'un monitoring adéquat et de protocoles d'évaluation.

RECOMMENDATIONS[b]

1) Renforcer la capacité de fournir des soins en situation de crise et d'urgences qui soient accessibles, réactifs et efficaces pour les enfants et les adolescents.

2) Approfondir et soutenir les compétences professionnelles dans le cadre des soins de santé mentale non spécialisés de façon à améliorer la qualité de l'évaluation, des soins et d'une liaison éventuelle avec les services spécialisés.

3) Développer la prévention, l'identification, l'intervention et la promotion ayant trait à la santé mentale chez les nourrissons et les enfants en bas âge, particulièrement au sein des populations vulnérables et démunies.

4) Etendre les services d'appui formel et informel tant pour les enfants/adolescents que leurs familles.

5) Renforcer la responsabilité des prestataires de soins pour les enfants souffrant de problèmes de santé mentale graves, multiples et complexes ; et développer et consolider la capacité à fournir des soins flexibles et assertifs dans leur milieu de vie.

6) Améliorer les compétences culturelles et linguistiques des dispensateurs de soins de santé mentale et des animateurs socio-éducatifs pour les enfants et les adolescents, dans le but de s'adapter aux spécificités culturelles des populations qu'ils servent.

7)

a/ Etablir un dialogue respectueux et multilatéral portant sur une vision partagée du système élargi de soins de santé mentale pour les enfants et les adolescents, en incluant toutes les parties prenantes pertinentes (y compris des représentants des enfants et des familles).

b/ Rédiger une charte éthique destinée à guider les dispensateurs de soins dans la formulation de réponses à la souffrance de l'enfant.

c/ Maintenir et renforcer les forums inter-sectoriels à différents niveaux institutionnels dans le but d'activer et de mobiliser la collaboration et la formation de réseaux sur une base continue.

[b] Le KCE reste seul responsable des recommandations faites aux autorités publiques

8) Obtenir de bonnes données qualitatives et quantitatives sur les besoins en et l'offre de services en santé mentale pour les enfants et les adolescents, pour potentialiser de façon efficace les établissements de soins répartis au niveau régional et afin de faciliter la formation de réseaux de soins régionaux.

9) Appliquer et définir des méthodes d'évaluation fondées sur les meilleures pratiques internationales, qui reflètent les spécificités nationales ou régionales, et en accord avec les orientations éthiques, dans but de renforcer la responsabilité, l'amélioration de la qualité et la multidisciplinarité au sein de la provision de soins de santé mentale pour enfants et adolescents.

10) Donner un signal politique clair qui encourage et récompense un climat innovateur et basé sur la pratique « evidence-based » dans le système belge des CAMHS, et rendre cela tangible par la mise en place rapide d'initiatives concrètes d'exécution.

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LIST OF ABBREVIATIONS

ABBREVIATION	DEFINITION
ADHD	Attention deficit hyperactivity disorder
AIGS	Association Interrégionale de Guidance et de Santé
AJ	Aide à la Jeunesse (French Community Youth care Institution)
ARC	Autism reference centres
ASBL Pétales	Association francophone de parents d'enfants avec troubles de l'attachement (French association of parents of children with attachment disorder)
ATD quart monde	Non-governmental organization protecting people in extreme poverty
AWIPH	Agence wallonne pour l'intégration des personnes handicapées (Walloon agency for integration of disabled persons)
BJB	Bijzondere jeugdbijstand (Flemish youth care)
CAF	Common assessment framework
CAMHS	Child and adolescent mental health care services
CAPA	Choice and partnership approach
CAR / CRA PSY	Centra voor ambulante revalidatie / Centres de rééducation ambulatoire (The ambulatory rehabilitation centres)
CAW	Centra voor algemeen welzijnswerk (Social service centres)
CBJ	Comités voor bijzondere jeugdzorg (Youth care office)
CGG / SSM	Centra voor geestelijke gezondheidszorg / Centres de santé mentale (Specialist ambulatory mental health care centres)
CH	Centre hospitalier (hospital center)
CIG	Centra voor integrale gezinszorg (Integrated family support service)
CLB	Centrum voor leerlingenbegeleiding (Education support team)
CMI	Cellules Mobiles d'intervention (Mobile intervention unit, assertive outreach)
CMP	Centres médico-psychologiques (Medico-psychological centres)

CMPP	Centres Médico-Psycho-Pédagogiques (Medico-psycho-pedagogical centres)
NRZV /CNEH	Nationale Raad voor Ziekenhuisvoorzieningen / Conseil National des Etablissements Hospitaliers (National council of hospital facilities)
COCOF	Commission communautaire française (French community commission)
COCOM	Commission communautaire commune (Common Community Commission)
CODE	Coordination des ONG pour les droits de l'enfant
CORC	CAMHS Outcome Research Consortium
COS	Centra voor ontwikkelingsstoornissen (Centres for developmental disorders)
CPMS	Centres Psycho Médico Sociaux (Psycho-Medico-Social Centres)
CQI	Continuous quality improvement
DGAJ	Direction Générale de l'Aide à la Jeunesse (French Community Youth care Institution)
DSM	Diagnostic and statistical manual of mental disorders
EACH Charter	European Association for Children in Hospitals Charter aka Leiden Charter
Epe	École des parents et des éducateurs (French association providing continuous education to parents and educators)
FAG	Forum des Associations de Généralistes Francophones (French Forum of the GPs associations)
FR	French speaking
OBC	Observation and treatment centres
FOR-K	Forensic K-beds (Child and adolescent psychiatric beds for youth offenders)
FPS	Federal public service
FSPST / PSTS	Fédération des Structures Psycho-Socio-Thérapeutiques / Psycho-sociale therapeutische structuren
FUNDP	Facultés universitaires Notre- Dame de la Paix , Namur
GGZ	Geestelijke Gezondheidszorg

GGZKJ	Geestelijke Gezondheidszorg voor kinderen en jongeren
GP	General practitioner
HONOSCA	Health of the nation outcome scales for children and adolescents
HSR	Health Services Research
HUDERF	Hôpital Universitaire Des Enfants Reine Fabiola / Universitair KinderZiekenhuis Koningin Fabiola (Queen Fabiola's Children University Hospital)
ICD-10	International Classification of Diseases, 10th Edition
IFISAM	Institut de formation à l'intervention en santé mentale (French training institute for mental health professionals)
IPPJ	Institutions publiques de protection de la jeunesse (Public service for youth protection)
IT	Intellectual Technology
IWSM	Institut Wallon pour la Santé Mentale (Walloon Institute for Mental Health)
KB / AR	Koninklijk besluit / Arrêté Royal (Royal decree)
KCE	Belgian Healthcare Knowledge Centre
KUL	Katholieke Universiteit Leuven
LBFSM	Ligue Bruxelloise Francophone pour la Santé Mentale
Lucas	Centrum voor zorgonderzoek en consultancy
Maison Vertes	Associations opened to children from birth to 3 years old and entourage
MPD / MPG / RPM	Minimal psychiatric data / Minimale psychiatrische gegevens / Résumé psychiatrique minimum
MPIs /IMEs	Medical pedagogical institutes / Instituts Médico-éducatifs
NGOs	Non-governmental organizations
NCHF / FNRZV /CNEH	National council of hospital facilities / Nationale Raad voor Ziekenhuisvoorzieningen / Conseil National des Etablissements Hospitaliers

NIHDI / RIZIV / INAMI	National institute for health and disability insurance / Rijksinstituut voor Ziekte-en Invaliditeitsverzekering / Institut national d'assurance maladie-invalidité
NL	Dutch speaking
NRZV / CNEH	Nationale Raad voor Ziekenhuisvoorzieningen / Conseil National des Etablissements Hospitaliers (National council of hospital facilities)
OBC	Observation and treatment centres
OEJAJ	Observatoire de l'Enfance, de la Jeunesse et de l'Aide à la Jeunesse (French Community Research Observatory)
ONE	Office de la naissance et de l'enfance (French Community Child and maternity centre)
PHARE	Personne Handicapée Autonomie Recherché / Service Bruxellois Francophone des Personnes Handicapées
PMS	Psycho-medico-social centre / Psycho-Medizinisch-Soziales Zentrum
RCT	Randomized Controlled Trial
SAI	Services d'aide à l'intégration (Integration support centre)
SAJ	Service d'aide à la jeunesse (Social care office)
SAJJNS	Services d'accueil de jour pour jeunes non scolarisables (Day centres for youngsters, unable to attend school)
SAP	Services d'aide précoce (Early care centres)
SAS	Services d'Accrochage Scolaire
SASPE	Services d'accueil spécialisés de la petite enfance (Specialised maternity centres)
SEN	Steunpunt expertise netwerken / Centres for expertise networks
Similes	Association supporting family of mental health patients
SOC	Systems of Care approach
SOS children	Equipes SOS Enfants (Confidential centres on child abuse and neglect)
SPJ	Service de protection judiciaire (Judicial protection centres)

SRJ	Services résidentiels pour jeunes (Residential youth centres)
SSM	Services de santé mentale (Mental health centre) or Soins de santé mentale (mental healthcare)
TDAH	Le trouble déficitaire de l'attention avec ou sans hyperactivité (French association for mental health)
UCL IRSS	Institut de recherche santé et société de l'Université catholique de Louvain
ULB	Université Libre de Bruxelles
ULg	Université de Liège
UNCRC	The United Nations Declaration on the Rights of the Child
UNICEF Belgique	United Nations Children Fund
UK	United Kingdom
US	United States of America
VAPH	Vlaams agentschap voor personen met een handicap (Flemish agency for disabled persons)
VK	Vertrouwenscentra Kindermishandeling (Confidential centres on child abuse and neglect)
VVGG	Vlaamse vereniging geestelijke gezondheid
VVA	Vlaamse Vereniging Autisme (Flemish association for mental health)
Watnu	Flemish association for parents of children with reactive attachment disorder
WHO	World Health Organization

SYNTHÈSE

1. INTRODUCTION, CONTEXTE ET MÉTHODES

1.1. Un système en proie à de graves difficultés

En 2005, lorsque l'Organisation Mondiale de la Santé (OMS) incite les Etats à adresserles préoccupations relatives à la santé mentale des enfants et des adolescents,[1,2] sa démarche est entre autres motivée par les difficultés rencontrées par de nombreux pays pour définir une stratégie cohérente et efficace répondant aux besoins complexes inhérents à ce domaine. L'enfant n'est pas la seule personne affectée par ces troubles. Son cercle familial et son entourage le sont souvent également, et de nombreux intervenants sont sollicités ou impliqués dans la prévention et la gestion de ces problèmes, avec à la clé un surcroît de complexité pour toute solution potentielle. Bien que toutes les parties prenantes s'accordent à considérer que le système belge actuel de soins de santé mentale pour enfants et adolescents soit en proie à de nombreux problèmes, il n'existe pas à ce jour de stratégie digne de ce nom en la matière. Comme dans de nombreux autres pays occidentaux, les réformes antérieures se sont concentrées sur le secteur de la santé mentale pour adultes. Ce secteur, jadis caractérisé par de multiples et larges institutions isolées, a progressivement été transformé en un dispositif de soins équilibré. Les soins sont proposés et fournis aussi près que possible du milieu de vie du patient, et seulement en institution si nécessaire.[3]

Il est patent que le système d'organisation des services de santé mentale pour enfants et adolescents, encore appelé CAMHS, requiert une approche sui generis. Le KCE a été chargé de mener à bien une étude de nature à servir de fondement à une réforme du système des CAMHS. Un rapport publié récemment par le Conseil National des Etablissements hospitaliers (CNEH) offre une analyse d'expert des problèmes actuels et des suggestions pour les besoins futurs dans le secteur des CAMHS en Belgique. Cet important document nous a énormément aidé pour la présente étude. Le cas échéant, nos conclusions et recommandations seront articulées avec son contenu.

1.2. Quatre raisons de procéder d'urgence à une réforme, adaptée aux besoins des enfants et des adolescents

Premièrement, les problèmes de santé mentale des enfants et des adolescents ne sont pas inhabituels. L'OMS évalue à 20% la prévalence des troubles et problèmes mentaux chez les enfants et les adolescents dans les pays occidentaux, dont 5% nécessitant une intervention clinique.[4,5] Deuxièmement, on observe un degré élevé de continuité entre les troubles des enfants et des adolescents, et ceux à l'âge adulte.[5] Selon l'OMS, environ 50% des troubles mentaux chez les adultes apparaissent avant l'âge de 14 ans.[6] Des interventions appropriées pendant l'enfance et l'adolescence seraient de nature à améliorer considérablement la santé mentale de l'ensemble de la population, tout en ouvrant de nouvelles perspectives d'avenir aux jeunes concernés.[2]

Troisièmement, il est généralement accepté qu'une politique appropriée de santé mentale pour enfants et adolescents devrait spécifiquement intégrer une dimension développementale. Les différentes étapes du développement des enfants et des adolescents ont un impact sur leur sensibilité aux troubles mentaux, sur le mode d'expression des troubles et sur la manière dont ils devraient être traités.[7, 8]

Finalement, le secteur des CAMHS s'est développé bien plus tard que le secteur pour adultes, et il ne se caractérise pas par l'existence de vastes institutions isolées de soins hospitaliers (la durée de séjour moyenne dans les services de pédopsychiatrie (lits-K) était de 40 jours en 2007).[9]

1.3. Un problème complexe, nécessitant une approche pluridimensionnelle

Eu égard à la complexité de la question et à la nature hautement contextuelle de toute solution pouvant être avancée, nous avons été tenus de combiner de manière innovante plusieurs approches différentes, et nous avons divisé l'étude en deux parties.

Une première partie, publiée en novembre 2011, a procédé à l'évaluation de l'état actuel des connaissances en matière d'organisation des CAMHS en effectuant une étude narrative de la littérature et une analyse des récentes réformes en Colombie britannique (Canada), aux Pays-Bas, au Royaume-Uni et en France.[9]

L'objectif de la seconde partie, qui fait l'objet du présent rapport, était de **profiler un futur système belge en matière de CAMHS,** dans le cadre d'un processus participatif (c'est-à-dire avec implication des parties prenantes) en se fondant sur les preuves (restreintes) découlant de la première partie[9] et d'autres études du KCE[10,11] (voir figure 1).

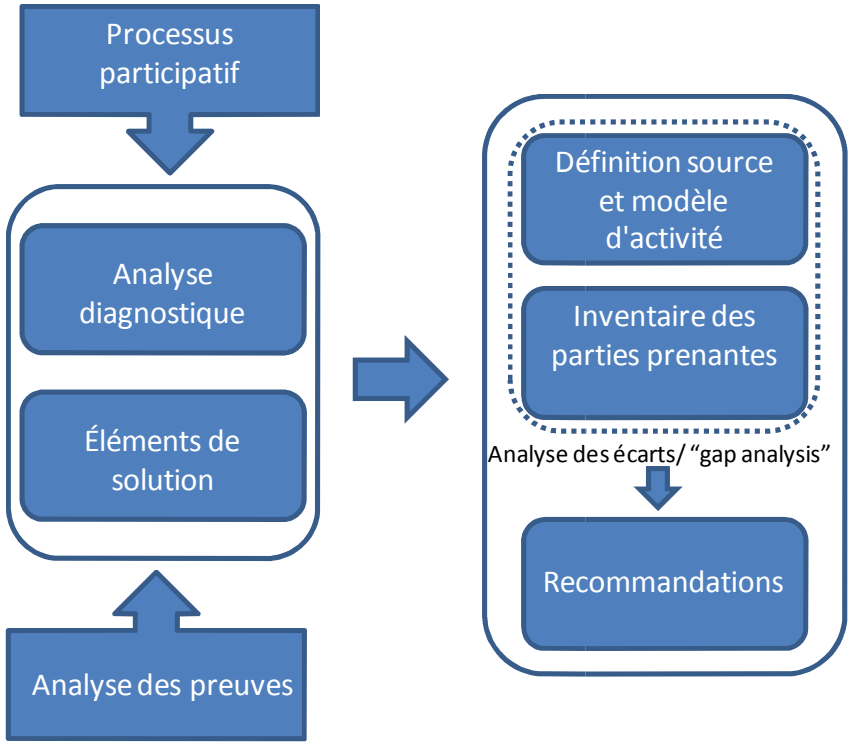
1.3.1. Méthodologie

La méthodologie utilisée pour solliciter la participation des parties prenantes au **processus participatif** est inspirée de la *Soft Systems Methodology*.[12] Dans le cadre de la présente étude, ces informations ont été complétées par une **analyse des preuves.**[9-11] Ces deux sources ont été utilisées pour:

(1) Mener à bien une **analyse diagnostique** du système des CAMHS existant, et

(2) Identifier les **éléments de solution** qui pourraient être intégrés à l'avenir dans un système plus efficace.

Figure 1: Trame conceptuelle de l'étude



Le processus participatif

Le processus participatif s'est articulé autour de cinq événements participatifs distincts pour des groupes de parties prenantes francophones et néerlandophones, car la différence de langue va de pair avec de considérables différences institutionnelles et thérapeutiques dans le domaine des soins de santé mentale (voir tableau 1).

Une étude documentaire et des informations ponctuelles récoltées auprès d'informateurs clés appartenant à notre réseau existant ont permis de constituer **une longue liste de parties prenantes CAMHS**. C'est à partir de cette liste que des personnes ont été invitées à prendre part à une ou plusieurs rencontres.

Le processus participatif s'est limité aux parties prenantes professionnelles, expertes et institutionnelles. Le point de vue des enfants et des adolescents n'a été intégré dans le processus que par le biais de représentants d'organisations de patients et de groupes d'entraide. Au total, 66 parties prenantes différentes ont pris part à une ou plusieurs rencontres. Un tiers environ des parties prenantes ayant participé à toutes les rencontres était constitué de pédopsychiatres (psychiatres infanto-juveniles). Cette surreprésentation des pédopsychiatres est délibérée, eu égard à leur compétence, à leur autorité en la matière et à leur rôle clé dans le système actuel, mais elle a induit un biais dans l'étude. On trouvera une description détaillée des profils des parties prenantes aux sections 2.2.2.1 et 2.2.2.2 du rapport scientifique.

1.3.2. Extrants

Deux ensembles d'extrants ont été produits, sur la base du diagnostic et des éléments de solution identifiés.

1. Dans une première phase, la **définition source** (finalité / raison d'être) et le **modèle d'activité** (ou le modèle conceptuel des activités requises) ont été formulés afin de délimiter les contours du futur système des CAMHS. Ils représentent un modèle idéal, sans contraintes de limites, statut légal, ressources, pouvoirs, etc. Cette étape a pour but de définir clairement la raison d'être du système des CAMHS, ainsi que les activités requises pour le mettre en oeuvre.
2. Dans la seconde phase, nous avons comparé le système des CAMHS belge actuel au système idéal (**cartographie des parties prenantes**), afin de repérer les chevauchements et les écarts (**gap analysis**). Cet exercice a débouché sur une vision très claire des plages de réforme prioritaires.

   Ce processus a généré le second extrant de l'étude, à savoir un éventail de **recommandations** d'interventions dans le système des CAMHS.

L'étude ne va pas jusqu'à détailler la gamme d'initiatives spécifiques à prendre pour concrétiser cette réforme. Les programmes, services et activités qui seront finalement retenus devraient toutefois s'inscrire dans le cadre tracé par la présente étude.

Tableau 1: Description du processus participatif

Activité	Période	Objectif de l'activité	Parties prenantes	Nombre de participants
Entretiens exploratoires	Juillet-Septembre 2011	Récolte de l'avis d'experts sur le système des CAMHS actuel. Perception des rapports de force et de la 'faisabilité culturelle' de changements	Parties prenantes faisant autorité dans le secteur des CAMHS	5 Francophones 5 Néerlandophones
Table-ronde initiale	Septembre 2011	Examen des avis des experts quant aux problèmes du système des CAMHS actuel, ainsi que des éléments de solution en vue de la mise en place d'un système plus efficace	Multiples profils: praticiens, gestionnaires, décideurs politiques, universitaires provenant de différents secteurs (soins de santé mentale ambulatoires et résidentiels, services de soins de premier recours, secteurs connexes tels qu'écoles, services d'aide sociale, justice pour mineurs)	17 Francophones 13 Néerlandophones
Atelier de validation	Octobre 2011	Examen et optimisation de la définition source et du modèle d'activité émergents	Multiples profils: praticiens, gestionnaires, décideurs politiques, universitaires provenant de différents secteurs (soins de santé mentale ambulatoires et résidentiels, services de soins primaires, secteurs connexes tels qu'écoles, services d'aide sociale, justice pour mineurs)	23 Francophones 20 Néerlandophones
Entrevues consultatives	Novembre 2011-Janvier 2012	Possibilité pour les intervenants clés de mieux exprimer leur opinion et d'élucider certains des points relevés lors de l'atelier de validation Prise en compte de multiples perspectives complémentaires, plus particulièrement de professionnels impliqués dans d'autres secteurs au service des jeunes	Intervenants faisant autorité dans le secteur des CAMHS et dans d'autres secteurs de prise en charge des jeunes	9 Francophones 9 Néerlandophones
Atelier de consolidation	Janvier 2012	Examen et optimisation du projet final de recommandations	Multiples profils: praticiens, gestionnaires, décideurs politiques, universitaires provenant de différents secteurs (soins de santé mentale ambulatoires et résidentiels, primary care services, secteurs connexes tels qu'écoles, services d'aide sociale, justice pour mineurs)	17 Francophones 17 Néerlandophones

2. ZONES PROBLÉMATIQUES IDENTIFIÉES PAR LES PARTIES PRENANTES

Au fil des rencontres avec les parties prenantes, plusieurs problématiques affectant le système des CAMHS actuel ont été inventoriées. Dans le présent paragraphe, nous nous limiterons à la synthèse des principaux points. En revanche, le rapport scientifique (Figure 2, chapitre 3.3) en fournit un paysage complexe (dans lequel pas moins de 36 problèmes sont representés, interreliés par 60 flèches), qui illustre **les interactions entre les différents points de friction**. Pour une description plus détaillée, consultez les points 3.2, 3.3, 4.6.1 et 5.1 du rapport scientifique.

2.1. Listes d'attente

Tant les services ambulatoires (CGG/SSM) que résidentiels se caractérisent par de longues listes d'attente pour les enfants et les adolescents. Ces listes d'attentes sont perçues comme **un facteur clé** de l'inefficacité du système, de l'image négative du secteur, des résultats décevants et d'une expérience sous-optimale, tant pour les enfants que pour leur famille, et ce pour les raisons suivantes:

- **Manque de diversité dans la provision de services**: les prestations sont essentiellement limitées aux services ambulatoires et résidentiels traditionnels. Les services ambulatoires sont perçus comme inefficaces et en déficit de personnel. On observe également une pénurie d'infrastructures de crise et d'urgences, ainsi que de 'soins assertifs' mobiles. En général, le système ne dispose pas suffisamment de solutions de prise en charge à domicile et de proximité, ainsi que de solutions suffisamment intensives pour constituer des alternatives aux traitements dans un contexte hospitalier ou résidentiel.
- **Les problèmes de capacité ont tendance à se renforcer mutuellement**: On se trouve confronté à une dynamique de 'renvoi de balle' d'un service à l'autre: le manque de capacité ambulatoire accroît la pression sur les dispositifs de crise, qui sont très vite saturés et qui renvoient les enfants vers des infrastructures résidentielles dans lesquelles ils ne devraient pas se trouver. Cette situation engendre une utilisation inappropriée et inefficace de la capacité disponible des infrastructures résidentielles onéreuses.
- **Une dynamique d'initiatives innovantes et expérimentales,** qui ne s'inscrivent pas dans le cadre stratégique au sens large. Ces initiatives apportent une réponse à des besoins réels, mais elles restent locales, atteignent très vite leur point de saturation et contribuent à la fragmentation. Elles font en outre fonction de soupapes de sécurité, qui relâchent la pression sur le système et qui contribuent ainsi à son inertie et à la résistance auxréformes. Par ailleurs, ces nouveaux services atteignent très vite leur capacité maximale, dissuadant les acteurs du secteur de prendre des initiatives similaires.

2.2. Accroissement de la demande

Les parties prenantes soulignent le net accroissement de la demande de services de santé mentale de la part des jeunes et de leur famille. Pour expliquer ce phénomène, ils avancent les raisons suivantes:

- **L'approche 'groupe cible'**, qui établit un catalogue de plus en plus détaillé des troubles mentaux et comportementaux, et renforce ainsi la demande qu'il génère, tant de la part des patients que des prestataires de services (car ces derniers souhaitent conserver leur raison d'être).
- Les problèmes de santé mentale semblent être **de plus en plus graves et complexes.** Il est possible que cette tendance soit liée aux évolutions sociétales plus larges.
- **Les listes d'attente dopent la demande**. Les patients, qui ont conscience de l'existence de listes d'attente, s'inscrivent souvent auprès de plusieurs services, en espérant ainsi obtenir une prise en charge plus rapide. Ceci gonfle les listes d'attente au-delà de toutes proportions réalistes. Ce problème est lié à **la nature éparse et non structurée de l'accès au système des CAMHS.** L'efficacité des services de première ligne (tels que le conseil en milieu scolaire, les services aux jeunes ou les médecins généralistes) et leur interaction avec les services spécialisés sont contrariées par la fragmentation et

par le manque de compétences en matière de santé mentale des services et soutiens non spécialisées.

2.3. Absence de vision d'ensemble claire

Malgré le consensus sur le fait que **les enfants ne doivent pas être considérés comme des petits adultes** (un des arguments justifiant une vision globale, une politique et un programme distincts pour les CAMHS), il existe de très nombreux autres points sur lesquels **il n'existe pas de consensus**. Faute d'appréhender clairement sa finalité, le système se laisse diriger par les intérêts des institutions, plutôt que par les besoins réels des jeunes et de leur famille.

Quatre dimensions clés ont emergé des rencontres entre parties prenantes comme essentielles à toute approche globale des CAMHS:

- **Périmètre** – Le système se concentre-t-il exclusivement sur l'enfant ou s'étend-il à l'ensemble de l'environnement social du jeune (y compris par ex. sa famille, son école et la collectivité)? Dans son état actuel, le système ne tient pas suffisamment compte de cet environnement social.
- **Rôle de l'enfant et de la famille –** Un dogme des soins/soutiens impulsés par la famille est peu utile. Il est souvent difficile de considérer les enfants et adolescents (ou leur famille/entourage) comme des experts de leurs propres troubles, et en conséquence comme partenaires et co-créateurs de leur propre itinéraire de prise en charge. Il serait désirable d'adopter une approche centrée sur la famille/entourage dans laquelle le niveau d'implication requis des enfants, adolescents et de leur famille est évalué au cas par cas.
- **Perspective développementale –** Les besoins et défis des jeunes personnes évoluent à mesure qu'ils sortent de l'enfance et entrent dans la vie d'adulte. Dans quelle mesure un système de soins de santé mentale est-il disposé et capable de moduler ses interventions en fonction de ces différentes phases développementales?
- **Approche 'groupe cible' vs. 'population'** – Il est nécessaire d'instaurer un équilibre entre la prise en charge de jeunes souffrant de troubles diagnosticables, et une politique de santé publique plus générale, qui comprend également des stratégies de promotion de la santé mentale, de prévention, de 'repérage' des troubles et d'intervention précoces.

2.4. Absence d'un cadre d'évaluation transparent

Eu égard à l'absence de vision et d'objectifs clairement définis, on observe également l'absence de définition claire des résultats poursuivis, qui servirait à profiler le système et à générer les services et soutiens requis pour produire les résultats spécifiés.

Les méthodes d'évaluation sont non existantes ou inappropriées. Les systèmes disponibles (tels que RPM/MPG) accroissent la charge administrative supportée par les praticiens, mais ils ne sont peu ou pratiquement pas utilisés pour l'aide à la prise de décision et d'optimisation continue de la qualité, que ce soit au niveau du système (meta) ou de la prestation de service.

L'analyse diagnostique des CAMHS: problème complexe ('wicked problem') et blocage

(Voir également la Figure 2)

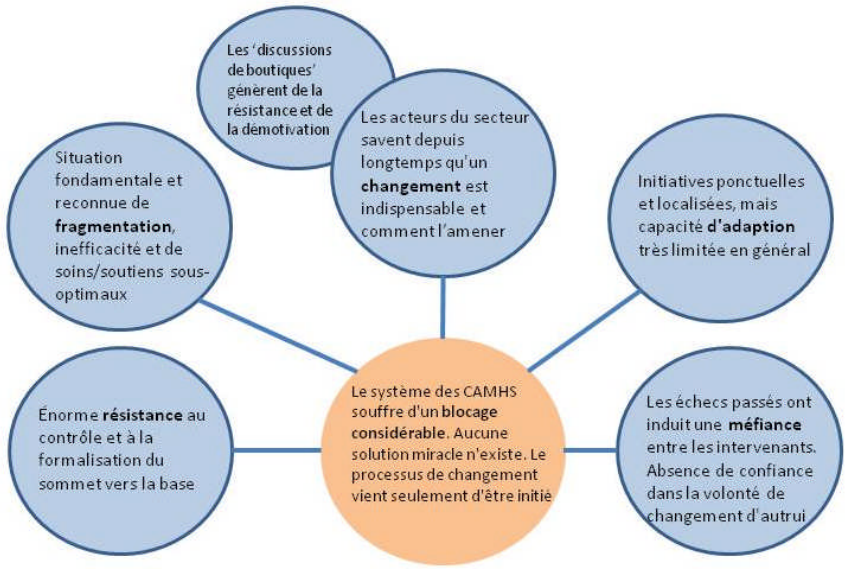
Les parties prenantes s'accordent à considérer comme problématique la situation actuelle dans le secteur des CAMHS. Plusieurs points problématiques ont été identifiés (voir 2.1- 2.4 ci-dessus), tels que de longues listes d'attente, une demande en constante augmentation, l'absence de vision claire d'ensemble et de cadre d'évaluation transparent. Les problèmes sont fondamentaux et manifestement interconnectés, tandis que le système souffre de fragmentation, d'inefficacité et de soins/soutiens sous-optimaux .

Malgré les multiples initiatives locales innovantes lancées par des acteurs de terrain au cours des dernières années, le système des CAMHS dans son ensemble n'est pas parvenu à s'adapter. Ces échecs passés ont induit une méfiance entre les intervenants et les secteurs concernés, ainsi qu'une absence de confiance dans la volonté de changement de l'autre.

Malgré ce constat, les parties prenantes sont farouchement opposées à un contrôle et une formalisation du sommet vers la base. En conséquence, on observe un antagonisme entre l'approche de la base vers le sommet, qui est vivement souhaitée, et la difficulté d'instaurer des pratiques organisationnelles et gestionnelles efficaces visant à favoriser la collaboration interinstitutionnelle.

Sur la base de ces différents éléments, nous concluons que le système des CAMHS est confronté à une problématique complexe ('wicked problem'), qui se traduit par un blocage. Manifestement, il n'y a pas de 'solution miracle' c.à.d les problèmes ne pourront être résolus par des mesures ponctuelles et à court terme.

Figure 2: Le système des CAMHS: un problème complexe ('wicked problem')



3. QU'EST-CE QU'UN FUTUR SYSTÈME IDEAL DES CAMHS DEVRAIT ÊTRE CAPABLE DE PROCURER?

3.1. Définition

Dans le présent chapitre, nous décrivons la formulation d'une définition source pour une réforme systémique du système des CAMHS belge, ainsi que les activités fonctionnelles que devrait produire un tel système (le 'Modèle d'Activités'). Ces deux éléments sont dérivés de la "Soft Systems Methodology", à savoir la méthodologie utilisée pour piloter le remodelage du système étudié.

Une **définition source** ne traduit pas la mission d'une organisation spécifique, mais exprime la **finalité** d'un système idéal, qui peut être concrétisée opérationnellement de multiples manières et qui peut impliquer des acteurs très divers. Il s'agit de la description de l'apport unique (la 'finalité') que le système est censé générer:

Un système mandaté par R et opérationnalisé par A, conçu pour faire X via Y pour les Usagers U afin de réaliserZ dans le cadre imposé par les contraintes de son Environnement E"[12]

Acteurs (A): personnes physiques et morales impliquées dans la concrétisation sur le terrain de la finalité du système.

Responsables (R): acteur(s) capables de changer ou d'arrêter le système, et pouvant donc être considérés comme responsables du système.

Contraintes de l'Environnement (E): circonstances extérieures qui influencent le fonctionnement du système.

L'élément Y détaille *la manière* dont la finalité est concrétisée. D'autres paramètres spécifient et détaillent la finalité fondamentale.

La définition source et le modèle d'activités (décrits dans la section suivante) sont fondés sur **les éclairages suivants**:

- L'analyse diagnostique (les goulets d'étranglement et les points de friction propres au système actuel, à éviter à l'avenir).
- Les points de vue éclairés dérivés des éléments de solution avancés par les parties prenantes.
- 'Systems of Care", le cadre dominant dans la littérature consacrée aux modèles organisationnels des CAMHS,[9]
- D'autres rapports du KCE dans ce champ de recherche,[10,11]
- L'avis rendu par le CNEH,[13]
- Des entretiens approfondis avec les parties prenantes (voir rapport scientifique, 4.5 et 4.6)

3.1.1. Finalité fondamentale d'un futur système des CAMHS en Belgique

"Le système des CAMHS offre une large gamme de services (X) aux enfants, aux adolescents et aux jeunes adultes présentant ou à risque de présenter des troubles mentaux , ainsi qu'à leur famille/entourage (U), afin d'aider ces jeunes personnes à vivre plus harmonieusement à la maison, à l'école, au sein de la collectivité et tout au long de leur vie (Z)."

Une large gamme de services (X) …

Les services prestés englobent la sensibilisation, la prévention et les services de santé mentale spécialisés et 'orientés soins/soutiens'. La définition d'un périmètre aussi large pour les services CAMHS est conforme à la littérature[2, 14] et à l'avis du CNEH,[13] et elle est soutenue par les parties prenantes (voir rapport scientifique, 4.1.1 et 4.1.2).

… prestés par de nombreux acteurs différents (A), dans et hors du cadre des soins de santé, …

Au stade actuel de la réflexion, les modalités concrètes d'organisation du futur système des CAMHS restent à définir. Toutefois, la finalité fondamentale comprise dans la définition source devra être concrétisée via l'apport de nombreux acteurs différents, professionnels de la santé et autres intervenants (services de santé mentale, services sociaux, services éducatifs, services de santé somatique, services pour moins-valides, services de lutte contre les assuétudes, services récréatifs, justice des mineurs, ainsi que potentiellement d'autres acteurs concernés.

… avec une responsabilité partagée (R), …

Le système des CAMHS envisagé peut être considéré comme étant mandaté par les instances tant fédérales que fédérées.

… mais dans le cadre de certaines contraintes (E), …

Sur la base des éléments de preuve évoqués ci-avant, il est évident qu'un budget limité, ainsi qu'une fragmentation institutionnelle et sectorielle notable, sont autant de paramètres extérieurs qui continueront à influencer considérablement le fonctionnement du système des CAMHS.

… pour tous les enfants, leur famille et leur entourage (U), …

Le système des CAMHS devrait aider tous les enfants à développer leurs aptitudes psychosociales, alors que la finalité fondamentale (procurer soins et soutiens) cible les enfants en proie à des difficultés. La répartition des ressources disponibles entre la population dans son ensemble et les jeunes souffrant de troubles de santé mentale est une question qui relève de la décision politique.

Il est en outre souhaitable de renforcer l'implication de la famille et de l'environnement de l'enfant (c.à.d. son établissement scolaire et la collectivité dans laquelle il vit). Les parties prenantes soulignent que la relation entre les enfants et leur famille n'est pas exempte de conflits et de complications. Dans certains cas, la famille est dysfonctionnelle ou est une des sources des troubles de l'enfant. En conséquence, les parties prenantes ont proposé de ne pas conserver le terme 'impulsé parla famille' (un aspect important du 'System of Care'[14]) comme élément qualificatif de la définition source.

… afin qu'ils atteignent un mieux-être, maintenant et pour le reste de leur vie (Z).

Le but ultime des services fournis à ces enfants et adolescents est d'accroître leur bien-être et leur potentiel de développement, tout au long de leur vie. Ce but ultime ne signifie pas pour autant que les résultats cliniques sont sans importance. Les parties prenantes se sont montrées réticentes à utiliser une terminologie trop 'fonctionnaliste' pour décrire ces résultats, et elles ont mis en exergue l'importance du 'bien-être' et du 'développement'. Cette position est conforme à la définition de l'approche

du 'Systems of Care',[14] ainsi qu'à l'avis du CNEH,[13] qui énonce que 'le rétablissement ou l'intégration' et autant que possible 'la participation maximale à la vie en société' doivent être les objectifs ultimes des soins/soutiens procurés.

3.1.2. Neuf qualifications additionnelles du mode de fonctionnement du système **(Y)**

Assortis d'un cadre éthique

Les professionnels doivent disposer de directives éthiques bien définies pour pouvoir gérer les tensions et dilemmes qui entourent l'enfant. Ce cadre éthique est un élément indispensable (mais pas suffisant) pour pouvoir contribuer au bien-être et au développement des jeunes personnes. L'approche du 'Systems of Care' met l'accent sur les droits de l'enfant comme socle éthique. L'accessibilité et la personnalisation des services, ainsi que l'encouragement à la prise de responsabilités par les enfants et les familles sont soulignés.[14] L'avis du CNEH met également en exergue l'accessibilité et la qualité des effectifs sous-tendant les services, mais il est plus réservé quant au rôle de la famille.[13]

Soutenus par des professionnels

Le fait d'étendre le périmètre du système des CAMHS au-delà des soins spécialisés et de mettre l'accent sur la prise en charge au sein de la famille et du milieu de vie ne signifient pas que n'importe qui peut être instauré prestataire de soins/soutiens. Lors des tables rondes, il a été répété à plusieurs reprises que la prestation des soins, au sens large, doit être subordonné en toutes circonstances à la détention de la compétence requise. L'avis du CNEH consacre un chapitre distinct à l'élargissement du fossé en matière de compétences et recommande la mise en valeur de la prise en charge de proximité, ainsi que l'encouragement à l'acquisition de compétences en matière de santé mentale par les prestateurs de soins/soutiens et éducateurs de secteurs connexes.[13]

Basés sur des preuves

Les preuves émergent de la pratique (Evidence-Based Practice) sont considérées comme ayant une valeur importante dans la littérature CAMHS internationale.[14, 15] Il existe des programmes, services et dispositifs de soins innovants dont l'efficacité n'a pas encore été établie, mais qui sont prometteurs et/ou sont considérés comme potentiellement bénéfiques dans l'optique de la résolution des problèmes importants pour les enfants, les adolescents et leurs familles. Le terme 'basé sur des preuves probantes (Evidence-Based) devrait offrir espace et soutien (tel que des programmes de recherche) à ces approches prometteuses, afin d'éviter que leur potentiel d'innovation soit mis en péril par l'obligation de se conformer à des protocoles validés de manière strictement scientifique.

De manière coordonnée

La fragmentation est considérée comme une des atteintes majeures à l'efficacité et à l'efficience du système des CAMHS en Belgique, mais également dans d'autres pays.[9] En conséquence, un surcroît de coordination est un des critères clés du futur système des CAMHS. Cette recommandation est partagée par les parties prenantes, la littérature internationale et les pratiques d'excellence mises en œuvre dans d'autres pays[9]. L'avis du CNEH recommande également une collaboration plus efficace entre les services de soins ambulatoires et résidentiels. Il propose également l'instauration d'une importante fonction de *consultation* et de *liaison*, chargée de la coordination avec les secteurs connexes.[13]

En réseau

Les réseaux de soins sont (généralement) des agrégats régionaux de différents prestataires de soins – des soins de base aux jeunes aux infrastructures résidentielles spécialisées – qui coordonnent leurs activités afin de contribuer à une ou plusieurs trajectoires de soins. Comme nous l'avons déjà souligné, les réseaux ont été une des caractéristiques importante de la réforme du secteur des soins de santé mentale pour adultes (ces concepts ont été enterinées par l'article 11 de la loi sur les hôpitaux).[3]

Personnalisés

L'approche 'Systems of Care' recommande un personnalisation de la prestation des soins, particulièrement aux jeunes personnes souffrant de troubles complexes de santé mentale.[14] L'approche enveloppante ('wraparound') agrège des services d'encadrement de proximité, des soins/soutiens de base et une prise en charge spécialisée en santé mentale en constellations souples et personnalisées.[9, 14] L'avis du CNEH plaide pour une 'approche multisystèmes' fondée sur un diagnostic et un programme de soins/soutiens individualisés.[13] Les parties prenantes ont fait valoir que les soins/soutiens sont trop souvent conditionnés de

manière ponctuelle par les services et capacités disponibles, plutôt que par les besoins du jeune et de sa famille (entourage).

Adéquats en matière de développement

Les parties prenantes ont recommandé d'inclure une perspective développementale dans le concept des CAMHS (voir supra).

Tenant compte de la diversité des cultures

Les prestataires de soins doivent être en mesure d'interagir avec le patient dans sa langue, et tenir compte de ses sensibilités culturelles. Il s'agit d'un des principes clés de l'approche 'Systems of Care'.[14]

Prestés dans un environnement aussi peu restrictif que possible

Les services doivent être prestés dans un environnement aussi peu restrictif que possible. Cette caractéristique clé de l'approche des 'Systems of Care' est appuyée par les parties prenantes. Elle est également défendue par l'avis du CNEH, qui plaide pour un déplacement du centre de gravité du système vers la prise en charge ambulatoire.[13]

3.1.3. Définition source étendue

À la lumière de ces qualifications additionnelles, la définition source peut désormais être formulée comme suit:

"Le système des CAMHS est une gamme de services guidés par des considérations éthiques, s'appuyant sur des professionnels et fondés sur des preuves, destinés aux enfants et adolescents souffrant de ou risquant d'être confrontés à des troubles de santé mentale, et à leur entourage. Ces services sont dispensés de façon coordonnée, personnalisée, adéquate par rapport au stade de développement du bénéficiaire et culturellement compétente, dans l'environnement à la fois le moins restrictif possible, cliniquement adéquat et le mieux adapté aux besoins de l'enfant. Son but est d'aider ces jeunes à atteindre un mieux-être et accroître leur potentiel de développement à la maison, à l'école, au sein de la collectivité et tout au long de leur vie."

3.2. Modèle d'Activités

Le '**Modèle d'Activités**' a été conçu sur la base de cette définition source, dans le but de représenter la manière dont le système réalisera sa finalité.

Un modèle d'activités est une représentation synthétique d'un système de travail, illustrant les activités à mener à bien pour que le système atteigne son objectif.

Ce modèle ne représente pas un système existant, mais bien un système idéalisé, capable de produire l'apport unique synthétisé par la définition source. Il se compose d'un ensemble d'*activités fonctionnelles*. Les entrées du modèle d'activités sont des verbes, et non des substantifs.

Il est très probable que des personnes représentant ou appartenant à un très large éventail de services et organisations contribuent à ces activités. En conséquence, les limites du modèle d'activités ne doivent pas être considérées comme des démarcations organisationnelles.

3.2.1. Modules fonctionnels

Le modèle se compose de 35 activités différentes, groupées en 9 modules fonctionnels:

1. planifier, dispenser et coordonner les soins;
2. gerer l'acces aux soins;
3. offrir des services de reponse aux crises;
4. developer et supporter la gamme de service;
5. supporter familles/proches et jeunes commes partenaires de soin;
6. conduire des activites de prevention et de developpement des competences de vie;
7. conduire des activites de reperage precoces;
8. developer et raffiner le modele de soins;
9. gestion du systeme.

3.2.1.1. Module 1 - planifier, dispenser et coordonner les soins

Le module fonctionnel nodal du système des CAMHS a pour finalité de dispenser des services. Le module ne détaille ni la nature ni la localisation des services dispensés. On distingue 5 activités fondamentales:

- **développer/ réviser le plan de soins personalisé**: Dans le cas d'un traitement ordinaire, cette activité ne nécessitera pas beaucoup de temps ni de ressources. Dans les cas plus complexes, qui requièrent une approche enveloppante (wraparound), par exemple, la somme d'efforts à consentir sera plus considérable.
- **fournir des services et du support** (à savoir la prestation concrète des services): Les services peuvent être simples et ponctuels, ou complexes et durables. Ils peuvent être dispensés à domicile, en milieu scolaire, dans un centre pour jeunes, dans une infrastructure ambulatoire, ou dans les services spécialisés d'un hôpital psychiatrique. Idéalement, ces services doivent être accessibles, personnalisés, culturellement adaptés et dispensés dans un environnement aussi peu restrictif que possible.
- **fournir une coordination des soins**: La coordination des services, dans et en dehors de la sphère du secteur de santé mentale, est une exigence incluse dans la définition source. En conséquence, des ressources doivent être allouées, de sorte que les personnes concernées puissent contribuer à cette activité.
- **surveiller et évaluer les progrès**: La prestation de soins aux jeunes et à leurs familles doit être évaluée en termes d'efficacité. Cette activité génère un indispensable feedback qui permet aux professionnels et aux jeunes (et à leurs familles) de prendre des décisions plus pertinentes quant aux modalités (nature et étendues) de la trajectoire de soins.
- **développer du support IT et collecter les données**: La coordination, la supervision et l'évaluation doivent nécessairement se fonder sur une certaine forme de gestion de l'information.

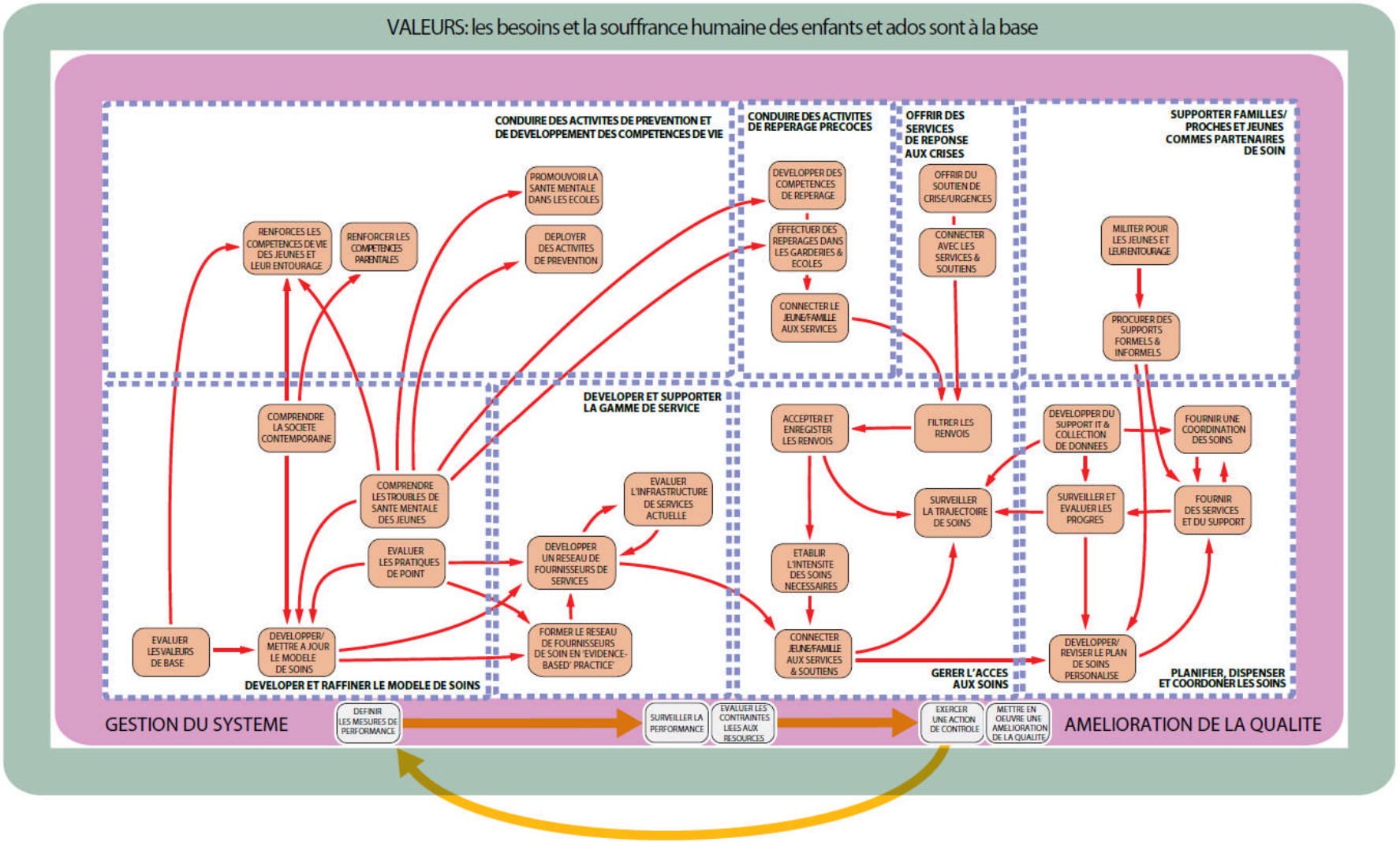
3.2.1.2. Module 2 - gérer l'accès aux soins

Un des modules fonctionnels régit l'accès des enfants et des adolescents au système de soins. Il se fonde sur quatre activités distinctes:

- **filtrer les renvois**: Les enfants et adolescents demandeurs de soins de santé mentale peuvent provenir de différentes sources (infrastructures d'urgence ou de crise, écoles, médecins généralistes, pédiatres, etc.) Quel que soit ce référent, leur cas doit faire l'objet d'un filtrage initial en fonction d'un protocole préalablement défini.
- **accepter et enregister les renvois**: Ce filtrage détermine si le jeune peut ou non bénéficier de soins de santé mentale. Dans l'affirmative, il est enregistré. La nature de cet enregistrement – centralisé ou non – n'est pas définie par le modèle d'activité.
- **établir l'intensité des soins nécessaires**: Après le filtrage et l'enregistrement, il convient de procéder à une évaluation de l'intensité des soins nécessaires.
- **connecter le jeune/famille aux services et soutiens**: En fonction de l'évaluation de l'intensité nécessaire, l'enfant/adolescent et sa famille sont mis en contact avec les services appropriés. Cette activité est ensuite connectée à l'activité 'Développer et Réviser le Plan de Soins Personnalisé', qui fait partie des modules de prestation des soins.

Les deux modules évoqués ci-avant constituent **l'axe prestation des services du système des CAMHS.** Ils doivent toutefois être complétés par un autre module fonctionnel pour que le système fonctionne conformément à la finalité et aux exigences de la définition source.

Figure 3: Modèle d'activité



3.2.1.3. *Module 3 - offrir des services de réponse aux crises*

La pénurie de services d'urgences et de réponse aux crises a été soulignée comme problème aigu dans l'analyse diagnostique. L'avis du CNEH recommande également d'allouer davantage de ressources à cette fonction.[13] Deux activités sont incluses dans le modèle d'activité:

- **offrir du soutien de crise/urgences**: Le modèle d'activités ne spécifie pas où et comment ces services doivent être fournis (par exemple par des équipes mobiles ou des cellules spécialisées dans des hopitaux psychiatriques ou des centres de soins de santé mentale de proximité).
- **connecter avec les services et soutiens**: Une fonction de liaison qui assure la connexion avec le module 'Gérer l'Accès Aux Soins'.

3.2.1.4. *Module 4 - développer et supporter la gamme de service*

Un des problèmes du système actuel réside dans l'étroitesse de l'éventail de services, et dans le fait qu'il repose trop sur des infrastructures résidentielles. Le 'Systems of Care' recommande de compléter les services ambulatoires et résidentiels par une prise en charge et un soutien des jeunes et de leur famille en milieu de vie.[14] L'avis du CNEH propose de déplacer le centre de gravité vers les services ambulatoires.[13] Quels que soient le mix de services et le réseau de prestataires qui sont jugés adéquats pour une certaine région (géographique), les intervenants devront investir du temps et de l'énergie dans leur mise en œuvre et leur développement. Le programme se compose de 3 activités:

- **développer un réseau de fournisseurs de services**.
- **évaluer l'infrastructure de services actuelle**: La mise en place de services alternatifs repose sur une analyse de l'écart entre la nature et la qualité des services qui existent déjà dans la région, et la demande en services.
- **former le réseau de fournisseurs de soins en 'evidence-based practice'**: Les services doivent bénéficier d'un encadrement professionnel, ce qui nécessite une formation.

3.2.1.5. *Module 5 - supporter familles/proches et jeunes comme partenaires de soin*

Un système de soins articulé autour de la famille attend de la famille et des autres aidants qu'ils prennent une part active à la formulation de la trajectoire de soins. Ils doivent être encouragés à le faire. Le module se compose de deux activités:

- **procurer des supports formels et informels**: Les familles doivent bénéficier d'informations, d'encadrement, de soutien par des pairs, de services de relâche et d'autres services formels et informels pour pouvoir remplir ce rôle.
- **militer pour les jeunes et leur entourage**: Une défense et promotion énergétique de la cause et des intérêts des jeunes et des adolescents souffrant de troubles mentaux et de leur famille est requise dans l'optique du développement de la gamme des services de support.

3.2.1.6. *Module 6 - conduire des activités de prévention et de développement des compétences de vie*

Il est établi que les programmes préventifs et les interventions précoces en milieu scolaire ont un effet positif sur la prévention de l'anxiété et sur la confiance en soi des enfants.[9] De même, l'approche du 'Systems of Care' réserve une place de choix à la prévention, tout comme l'avis du CNEH.[13] Le module de prévention et de développement des compétences de vie se compose de quatre activités:

- **déployer des activités de prévention:** Des activités de prévention clés, auxquelles peuvent être associées divers types d'interventions, dans différents cadres.
- **promouvoir la santé mentale dans les écoles**: Cette activité se concentre essentiellement sur les éducateurs et les enfants en milieu scolaire.
- **renforcer les compétences de vie des jeunes et de leur entourage**. La vie moderne est plus stressante et plus exigeante (obligation de réussir, évolution constante des technologies, consumérisme, etc.) et impose aux enfants et à leur famille de disposer de compétences de vie appropriées.

- **renforcer les compétences parentales**. Les parties prenantes ont souligné que la vulnérabilité des enfants aux problèmes de santé mentale, ainsi que ces problèmes en eux-mêmes, est en progression en raison de l'érosion des compétences parentales. Cette activité a pour but de remédier aux causes parentales/environnementales des troubles de santé mentale.

3.2.1.7. Module 7 - conduire des activités de repérage précoces

Toutes les parties concernées s'accordent à reconnaitre que le repérage des troubles de santé mentale chez l'enfant est essentiel, dans la mesure où une intervention précoce peut avoir un impact considérable sur leur développement et sur la qualité de vie de l'enfant et de sa famille, et éviter des interventions thérapeutiques ultérieures. Ce module est connecté au module 'Gérer l'accès Aux Soins', ainsi que plus loin au module 'Planifier, Dispenser et Coordonner les Soins'. Il se compose de trois activités liées au repéragee:

- **développer des compétences de repérage**: Les compétences doivent être développées auprès des parents, des gardiennes, des éducateurs et du personnel des écoles et des centres de soins pour enfants.
- **effectuer des repérages dans les garderies et écoles**.
- **connecter le jeune/famille aux services**: Selon les résultats du repérage, les services d'identification précoce doivent interagir avec le système de soins de santé mentale.

3.2.1.8. Module 8 - développer et raffiner le modèle de soins

Les tables rondes ont clairement indiqué qu'il est important pour le système des CAMHS de disposer d'une capacité d'apprentissage et d'auto-réparation. Cinq activités sont inclues pour offrir au système cette capacité d'adaptation et de réagencement du modèle de soins en fonction des évolutions sociétales, de l'évolution des attentes à l'égard des enfants, ainsi que des progrès dans la pratique des soins de santé mentale:

- **développer/mettre à jour le modèle de soins**: Le système des soins de santé mentale pour enfants et adolescents doit intégrer une fonction de remise en question et d'adaptation, afin de suivre les évolutions de la société et l'évolution des pratiques en santé mentale.
- **comprendre la societé contemporaine**: Le modèle de soins doit tenir compte des tendances sociales dominantes et y apporter une réponse. Les intervenants dans le système des CAMHS devront veiller à accorder à ces évolutions toute l'importance qu'elles méritent, fût-ce de manière informelle.
- **évaluer les valeurs de base**: Il est indispensable de procéder à une évaluation régulière de la pertinence des valeurs cardinales du système, ainsi que de leur capacité à guider l'action des professionnels de la santé et des décideurs politiques.
- **comprendre les troubles de santé mentale des jeunes**: La société évolue, tout comme l'efficacité des méthodes scientifiques visant à comprendre le mode de fonctionnement de l'esprit des enfants. Pour suivre ces évolutions, il est bien sûr indispensable de mobiliser les ressources requises.
- **évaluer les pratiques de pointe**: Des études sont nécessaires, afin d'évaluer les avancées dans les pratiques et techniques de soins de santé mentale.

3.2.1.9. Module 9 - gestion du système

Quelles que soient les modalités d'organisation et de mise en œuvre des activités des huit autres modules, il est indispensable d'évaluer l'efficacité et l'efficience de l'ensemble du système. Ce module se compose de cinq activités:

- définir les mesures de performance;
- surveiller la performance;
- évaluer les contraintes liees aux ressources;
- exercer une action de contrôle;
- mettre en oeuvre une amélioration de la qualite.

3.3. Conclusion

3.3.1. Contributions clés Contributions clés Contributions clés

Trois transformations fondamentales.

Le modèle d'activités est le vecteur de trois mutations fondamentales:

- Au niveau de l'enfant et de sa famille, le système des CAMHS doit garantir l'atténuation de la souffrance de l'enfant;
- Au niveau des services, le système des CAMHS doit favoriser et promouvoir une meilleur coordination;
- Au niveau de la politique, le système des CAMHS doit garantir sa fidélité aux valeurs clés, et sa capacité d'adaptation pour ce faire;

La palette de 35 activités interdépendantes, groupées en 9 modules fonctionnels, a pour but d'assurer la concrétisation de la finalité du système.

Générique en termes de solutions, spécifique en termes de critères

D'une part, le modèle d'activités est générique et permet différentes approches opérationnelles. C'est un de ses atouts, car il peut s'adapter aisément à différents contextes régionaux.

Le modèle d'activités peut aussi être spécifique pour certains groupes cibles.

Les modules de prévention et de repérage précoce du modèle se révéleront très importants pour la grande majorité des jeunes ne souffrant pas de troubles mentaux, ou de troubles mentaux légers. Pour les jeunes en proie à des troubles plus complexes, le module 'Planifier, Dispenser et Coordonner les Soins' sera le plus important (ainsi que toutes les autres activités qui le supportent).

Le modèle d'activités est même en mesure d'intégrer différents équilibres entre une approche 'ensemble de la population' et une approche 'groupe cible'. En fonction de la pondération de chacune d'entre elles dans la politique d'un pays ou d'une région, davantage de ressources peuvent être affectées aux activités de prévention et de développement des compétences, plutôt qu'aux activités de repérage et de traitement.

D'autre part, le modèle d'activités reflète la spécificité du modèle de soins multisystème coordonné envisagé dans le cadre de la présente étude. Le module de support des enfants et de leurs familles veut leur donner un plus grand pouvoir de décision dans la manière dont les soins/soutiens sont dispensés. Le module 'Développer et Supporter la Gamme de Service' attire l'attention sur la nécessité d'innover en permanence, afin de proposer un large éventail de services, allant au-delà des services ambulatoires et résidentiels conventionnels. Les activités de coordination et de gestion de l'information du module 'Planifier, Dispenser et Coordonner les Soins' reconnaissent explicitement la nécessité de collaborer et de procéder à des échanges d'informations au sein du secteur de la santé mentale et au-delà. Les activités combinées 'Développer et Réviser le Plan de Soins Personnalisés avec le Jeune et sa Famille comme Partenaires de Soin' souligne l'importance des approches 'assertives' dans la prestation des soins.

Dans l'ensemble, le modèle d'activités traduit les caractéristiques distinctives d'une philosophie des soins de santé mentale émergente. Comme souligné ci-avant, le modèle d'activités ne devrait pas être dissocié de la définition source, à laquelle il est étroitement associé et qui lui fournir le cadrage requis.

3.3.2. Déconstruire, pour davantage de créativité

Comme on pouvait s'y attendre, le modèle d'activités a de nombreuses caractéristiques communes avec des modèles conceptuels proposés par ailleurs. C'est également le cas pour **l'avis du CNEH,**[13] qui propose un système de soins de santé mentale pour enfants/adolescents composé de 6 modules: une fonction de soins (semi-)résidentiels; une fonction de services ambulatoires; une fonction de prévention, repérage, intervention précoce; une fonction de soins d'urgences, de crise et assertifs; une fonction d'interconnection avec les services de soins à domicile et de proximité; ainsi que divers modules de soins spécialisés pour des groupes cibles spécifiques (assuétudes, jeunes délinquants).

Les deux approches contiennent des fonctions de prévention, de repérage, d'intervention précoce, de crise et d'urgences. La fonction de liaison est explicitement présente dans les deux modèles. Malgré ces points communs manifestes, **la perspective adoptée par les deux modèles conceptuels est différente.** L'avis du CNEH[13] fait nommément référence aux infrastructures ambulatoires et résidentielles et est toujours très proche d'une manière de penser hospital-centrique. En revanche, notre

modèle d'activités ne spécifie pas l'*endroit* où les soins doivent être prodigués. Il indique seulement que c'est sur la base d'une évalation de l'intensité des soins requise que les soins doivent être programmés, dispensés et supervisés. En ce sens, il entreprend de déconstruire les modèles offrant des solutions fondées sur les droits acquis des structures existantes, de ce fait libérant une réflexion créative centrée sur les objectifs fondamentaux que le système est sensé servir. Par exemple, comme la définition source stipule, entre autres, que **les services seront fournis dans l'environnement le moins restrictif et que, dans la mesure du possible, la priorité sera accordée aux services à domicile et en milieu de vie**, ce sont ces critères qui devraient conditionner les décisions prises au niveau politique et du terrain quant aux types de services et soutiens à mettre en œuvre, en fonction du context.

4. DU MODÈLE CAMHS ENVISAGÉ AUX RECOMMANDATIONS

La phase suivante de l'étude est celle de la **cartographie des parties prenantes.** Cette phase a été entreprise pour obtenir une image détaillée des chevauchements et des écarts entre le modèle d'activités et le système actuel (voir le rapport scientifique, chapitre 4.4, pour des explications détaillées et des illustrations).

Dans une première phase, toutes les parties prenantes impliquées dans le système *actuel* des CAMHS sont positionnées dans un diagramme de base. Ensuite, les activités du modèle d'activités (c.à.d. du système *idéal*) sont reliées aux acteurs.. Dans une troisième phase, quatre types de relations entre les acteurs sont représentés (collaboration, financement, prestation de soins/soutiens et défense des intérêts).

Ce processus révèle non seulement les écarts et chevauchements, mais il illustre aussi une fois de plus **la complexité opérationnelle et réglementaire, ainsi que la multidimensionnalité** du système des CAMHS, de même que **le potentiel pour de nombreux acteurs de contribuer aux diverses activités qui assurent le bon fonctionnement du système des CAMHS.**

En dernier lieu, des recommandations stratégiques ont été formulées pour combler les lacunes observées dans le système des CAMHS actuel. Ces recommandations sont fondées sur les éléments de solution générés par:

- Les différentes rencontres avec les parties prenantes;
- La revue de la littérature et la comparaison internationale de la 1ère partie;[9]
- Des études antérieurs du KCE dans ce domaine;[10,11]
- L'avis du CNEH.[13]

Neuf recommandations ont été proposées pour soutenir une transition entre le système des CAMHS actuel, fragmenté et cloisonné, vers une provision de soins et de soutiens efficace, coordonnée et guidée par des considérations éthiques, et qui s'étend par-delà les frontières sectorielles et programmatiques. Une version provisoire de ces recommandations a été soumise aux parties prenantes dans le cadre d'un atelier de consolidation. Dans l'ensemble, ces recommandations ont été jugées pertinentes et conformes au périmètre de réforme des CAMHS attendu par les experts (voir le point 5.4 du rapport scientifique). Le chapitre ci-après contient une description des recommandations, ainsi que:

- Une synthèse des problèmes qu'elles ont pour but de résoudre;
- Les éléments de solution qui ont été découverts durant l'étude;
- Les questions qui devront être prises en compte lors de la mise en œuvre des recommandations.

5. RECOMMANDATIONS

Recommandation 1

Renforcer la capacité de fournir des soins en situation de crise et d'urgences qui soient accessibles, réactifs et efficaces pour les enfants et les adolescents.

Le problème et ses causes

Les conséquences négatives de la pénurie de services d'urgences et de crise, qui sont essentiellement l'apanage des services de soins de santé mentale 'spécialisés' (voir chapitre 3.2.3 du rapport scientifique) se ressentent à de multiples niveaux: elles aggravent les problèmes de santé mentale des enfants et de leurs familles, induit de la frustration et du découragement dans le chef des prestataires de soins et favorise une utilisation inappropriée des infrastructures de soins existantes, essentiellement spécialisées et résidentielles.

Pistes de solutions

La remédiation à la pénurie de capacité d'urgences et de crise a fait l'objet tant d'une étude antérieure du KCE[10] que de l'avis du CNEH.[13]

La revue de la littérature réalisée par le KCE révèle une tendance manifeste vers des modèles complémentaires de prestation de soins psychiatriques intensifs, y compris des services de proximité, des équipes d'intervention de crise et une prise en charge ambulatoire et résidentielle adaptée à l'âge. Le KCE recommande de conceptualiser les soins psychiatriques d'urgences comme une 'fonction' distincte, plutôt que comme un service ou département spécifique, en donnant la priorité aux soins non résidentiels.[10]

L'avis du CNEH[13] propose d'apporter une réponse intégrée aux situations urgentes ou aiguës liées à un trouble de santé mentale par le biais de trois fonctions distinctes: les soins d'urgences, les soins de crise et les soins assertifs. Les soins d'urgences sont généralement liés aux complications médicales (somatiques) et nécessitent une intervention immédiate.

Les crises liées à la santé mentale s'accommodent d'un temps de réponse de quelques jours. Les soins assertifs se présentent sous la forme d'un processus adaptatif, durable et mobile d'implication au sein de leur milieu de vie des personnes qui sont le plus dissociées de la société et de ses services, et qui sont donc les plus difficiles à atteindre. Les parties prenantes qui ont été consultées dans le cadre de la présente étude encouragent toutes les parties travaillant avec des enfants souffrant de troubles de santé mentale– y compris l'aide à la jeunesse et les services aux moins-valides – à prendre leurs responsabilités et à apporter une réponse appropriée aux situations urgentes et aiguës.

Éléments à prendre en compte dans la phase de mise en oeuvre

Une capacité de crise additionnelle pourrait être opérationnalisée d'autres manières, pas mutuellement exclusives:

1. Réserver un pourcentage prédéfini (K) des lits résidentiels aux admissions de crise (cette mesure nécessiterait une injonction fédérale);
2. Constituer des unités locales et autonomes, pas nécessairement attachées à un hôpital (mais à un centre local de soins de jour);
3. Mettre sur pied des équipes transsectorielles, pluridisciplinaires, mobiles et interconnectées, actives au niveau régional ou dans un 'bassin de soins', afin de soutenir les services non spécialisés de santé mentale. Ces équipes mobiles pourraient également intervenir dans des trajectoires courtesde soins assertifs sur demande (voir aussi l'avis du CNEH).

Un point de contact composé de collaborateurs transectoriels devrait être établi pour garantir une intervention de crise à tout moment (24 heures sur 24 et 7 jours sur 7, avec pour directive de refuser les enfants et adolescents sans évaluation appropriée de la situation)[10].

Le renforcement de la capacité de crise et d'urgences devrait être régi par deux principes clés: le service doit **être implanté dans un réseau transsectoriel de prestataires de soins**, et il doit être organisé de manière flexible en termes de localisation de la prestation, de préférence **dans un environnement aussi peu restrictif que possible**.

Les réseaux devraient s'organiser par eux-mêmes, bénéficier d'incitants lorsqu'ils offrent une couverture adéquate, lorsqu'ils sont disponibles et lorsque leurs soins sont de qualité. Tous les intervenants impliqués doivent leur allouer les ressources requises et renforcer leur compétence en matière de soins de crise, de manière à ce que chacun d'entre eux puisse

assumer ses responsabilités, particulièrement à l'égard des jeunes qu'ils ont traités. Des ressources fédérales complémentaires seraient nécessaires pour financer les 'lits de crise' qui ne font en principe pas partie du contingent de lits K des hôpitaux mais qu'ils gonflent actuellement par défaut.

Recommandation 2

Approfondir et soutenir les compétences professionnelles dans le cadre des soins de santé mentale non spécialisés de façon à améliorer la qualité de l'évaluation, des soins et d'une liaison éventuelle avec les services spécialisés.

Le problème et ses causes

Une des principales difficultés auxquelles sont confrontés les prestataires de soins de santé mentale réside dans la manière aléatoire dont les enfants aboutissent dans des infrastructures résidentielles de soins spécialisés. La qualité du repérage des enfants et de leurs familles en quête de support et leur aiguillage progressif vers des services plus spécialisés souffrent de la fragmentation chronique du système. Les lacunes du système se manifestent clairement dans les cas de crise et d'urgences aiguës (voir Recommandation 1) et lorsque les jeunes souffrent de troubles complexes et multiples de santé mentale (voir Recommandation 5). Dans d'autres cas moins extrêmes, il arrive aussi que les trajectoires de soins soient tortueuses et incohérentes, avec à la clé un surcroît de souffrance des enfants/adolescents et de leurs familles.

Un autre problème épinglé par les intervenants a trait aux relations tendues entre les services de première ligne (ou ligne zéro) et les cliniciens, dû en partie à des facteurs déontologiques et procéduraux, ainsi qu'à des expériences antérieures peu heureuses.

Pistes de solutions

En matière de soins de santé mentale, on considère de plus en plus souvent comme une bonne pratique le fait d'adapter à la complexité du cas le niveau d'expertise clinique au point d'entrée dans le système. La méthode Choix & Partenariat – une approche innovante, mais pas encore validée en tant que telle, utilisée dans nombre d'hôpitaux psychiatriques en Belgique – incarne ce principe[a].[9]

Les intervenants n'ont pas été favorables du principe du 'point d'accès unique', en tirant argument du peu de succès de ce principe dans les pays où il a été appliqué.[9] Ils plaident en revanche, conformément à l'avis du CNEH,[13] pour un renforcement des compétences de base dans les services de conseil et de soins non spécialisés (tels que les écoles, les médecins généralistes, l'aide à la jeunesse et les centres de jour) et pour la possibilité d'avoir recours à des compétences spécialisées, le cas échéant, sur base consultative.[9] Parmi les exemples évoqués, citons le programme de formation des médecins de première ligne en Colombie-Britannique[9] et la mise au point de normes intersectorielles (savoirs, aptitudes et compétences) pour l'ensemble du personnel au Royaume-Uni.[9]

Éléments à prendre en compte dans la phase de mise en oeuvre

Le renforcement des compétences liées à la santé mentale dans des cadres non spécialisés requiert une maîtrise suffisante des **cadres juridiques** applicables aux CAMHS.

La mise en œuvre de la présente recommandation touche tous les professionnels impliqués dans les CAMHS. Un rôle clé doit être réservé aux **médecins généralistes**.[16] Une évaluation des 'projets thérapeutiques' belges révèle toutefois que l'intégration de du secteur des soins de santé primaire dans les CAMHS pose un certain nombre de problèmes.[11] Les parties prenantes consultées dans le cadre de la présente étude soulignent la nécessité de reconnaitre l'importance des médecins généralistes, de leur fournir une formation adéquate et de leur allouer une compensation financière pour les longues consultations. Par ailleurs, il convient de résoudre le problème du secret professionnel, derrière lequel les professionnels de la santé mentale semblent se retrancher.

Des **mesures relativement simples**, telles que le télécoaching (via Internet ou par téléphone) par des psychiatres, peuvent aussi faire une grande différence. Enfin, les professionnels qui font le lien entre différentes lignes ou secteurs devraient bénéficier d'une formation adéquate (et même d'une qualification) en qualité de médiateurs de réseau dans les CAMHS.

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a http://www.capa.co.uk/

Recommandation 3

Développer la prévention, l'identification, l'intervention et la promotion ayant trait à la santé mentale chez les nourrissons et les enfants en bas âge, particulièrement au sein des populations vulnérables et démunies.

Le problème et ses causes

L'Organisation Mondiale de la Santé fait état d'un haut niveau de prévalence des troubles de santé mentale chez les enfants et les adolescents.[5] L'OMS souligne que les troubles qui se manifestent durant l'enfance ou l'adolescence se prolongent généralement à l'âge adulte.[6]

De nombreux facteurs – notamment sociaux, économiques, culturels, éducatifs, résidentiels et familiaux – influencent la sensibilité à ce risque.[17] Les intervenants ont dès lors fait référence aux groupes à risques suivant: les enfants de parents adolescents ou de parents souffrant eux-mêmes de handicaps et de troubles mentaux, les enfants victimes de traumatismes (tels que le suicide ou la mort violente d'un parent) ou ayant été exposés à des violences physiques ou psychologiques, les enfants présentant un retard de développement, ou encore les très jeunes enfants souffrant d'anorexie.

Pistes de solutions

Au niveau international, la tendance est à l'allocation d'un surcroît de ressources à la prévention.[9] La Revue Stratégique Britannique des Inégalités en matière de Santé Après 2010[18] recommande d'affecter davantage de ressources à la prévention à un stade précoce du développement d'une personne afin de réduire de manière optimale les inégalités en matière de santé durant sa vie ultérieure. De même, l'avis du CNEH[13] considère la prévention et le dépistage précoce comme faisant partie des quatres responsabilités cardinales d'un système des CAMHS. Il recommande de renforcer les initiatives valables et innovantes déjà prises dans ce domaine.

Les intervenants sont également convaincus des retours sur les investissements en matière de prévention, de repérage et d'intervention précoce. Ils insistent notamment sur le ciblage des **très jeunes enfants et des enfants à naitre,** mais aussi des **groupes défavorisés et vulnérables** ('prévention sélective'[9, 19]).

En outre, les parties prenantes préconisent d'élargir les activités de prévention au-delà des groupes vulnérables, afin d'inclure **tous les jeunes**, y compris ceux qui ne souffrent pas de problèmes mentaux ('prévention universelle'). Les intervenants ont insisté sur la nécessité de trouver un équilibre entre le ciblage des jeunes souffrant de troubles diagnostiquables et cette 'approche de santé publique' plus vaste. Par ailleurs, la Partie I de cette étude, nous a appris que des programmes de prévention et de renforcement de la résilience dans le cadre scolaire se sont révélés efficaces.[9]

Éléments à prendre en compte dans la phase de mise en œuvre

La prévention en santé mentale figure au nombre des compétences des **autorités fédérées**. Les dispensateurs de soins de première ligne – y compris les médecins généralistes, les centres de santé communautaires, les organisations d'aide aux familles (Kind & Gezin, ONE), les services d'orientation scolaire (CLB/PMS) et autres parties – jouent un rôle essentiel dans le développement des activités de prévention. Leurs compétences en santé mentale d'enfants et adolescents doivent être renforcées (Recommandation 2). S'agissant en particulier des très jeunes enfants, certaines parties prenantes plaident en faveur d'une approche plus assertive et de sensibilisation en matière de soutien familial et d'orientation scolaire. Des lieux tels que les Maison Vertes[b] et l'initiative émergente 'Huis van het Kind' (Kind & Gezin) offrent des endroits accessibles pour intégrer des compétences spécialisées en matière de santé mentale dans les activités de prévention.[9] En conséquence, on recommande des partenariats avec les crèches. Les parties prenantes ont également épinglé les retombées potentiellement indésirables de la détection précoce, notamment l'enfermement dans un diagnostic et la stigmatisation.

[b] http://www.lesmaisonsvertes.be/

Recommandation 4

Étendre les services d'appui formel et informel tant pour les enfants/adolescents que leurs familles.

Le problème et ses causes

Il existe actuellement des **carences de taille dans l'offre de services,** en particulier au niveau des services à domicile et au sein de la communauté. Parmi ces derniers, nous visons aussi bien les services ambulatoires dispensés par des professionnels de la santé que les aides plus informelles fournies par les para-professionnels et leurs pairs.

Les services de répit, qui offrent une relève temporaire de courte durée aux soignants de proximité des membres de leur famille, sont bien développés dans les soins aux handicapés mais pas aux patients souffrant de CAMHS.

Un autre problème révélé par la présente recherche est l'**absence** d'une **organisation représentant spécifiquement les jeunes souffrants de troubles de santé mentale ainsi que d'une puissante organisation représentative des familles de ces jeunes** pour jouer le rôle de défenseur et de partenaire au sein du système.

Pistes de solution

Un élargissement des services d'appui renforcerait deux évolutions essentielles dans les soins de santé mentale. Tout d'abord, un tel élargissement s'inscrit dans le sillage d'un intérêt croissant pour une **approche de santé publique** en matière de santé mentale qui englobe la prévention, l'identification, l'intervention précoce et la promotion (Recommandation 3). Ensuite, il contribue à un **modèle de soins davantage basé sur la collectivité** et qui cadre avec la tendance dominante qui veut que les soins soient dispensés dans un environnement qui soit le moins restrictif possible. Les services d'appui formels et informels représentent un élément essentiel dans l'approche du Systèms of Care et peuvent prendre de multiples formes[14]. En voici une liste non exhaustive[14, 20]:

- consultations de santé mentale;
- éducation des jeunes et des familles;
- loisirs thérapeutiques, mentorat thérapeutique;
- services parascolaires (pour les parents et les enfants);
- activités d'intégration et de socialisation (par ex., dans les clubs de sport et de jeunes);
- services de relève (pour les parents et les autres dispensateurs de soins);
- soutien aux jeunes par les pairs; soutien aux familles par les pairs;
- services d'appui pour faciliter la transition vers la vie adulte.

Les services sont offerts dans le milieu de vie des personnes – domicile, école, espaces récréatifs – ou dans des centres de santé communautaires. **Un seul mot d'ordre: proximité.** Cette responsabilité incombe essentiellement aux responsables de l'aide à la jeunesse et aux organisations d'aide aux familles, financées par des entités fédérales, mais également aux fora régionaux intersectoriels qui peuvent offrir l'environnement pour concevoir et incuber ces types de services (voir également les Recommandations 2 et 7).

En dépit du fait que le rôle critique des services d'appui soit abondamment cité dans la littérature,[21] la plupart de ces démarches font partie des interventions éclairées par la pratique.

Éléments à prendre en compte dans la phase de mise en œuvre

Outre les professionnels de l'aide à la jeunesse et de l'éducation qui font partie des dispensateurs de soins financés par le gouvernement, des professionnels émanant du privé pourraient également être admis dans le réseau de dispense de soins. Les associations de patients et les non-professionnels peuvent contribuer via une assistance concrète, un soutien émotionnel et l'acquisition de compétences. Les parties prenantes ont émis l'avis selon lequel une qualification idoine et une allégeance aux principes moraux régissant les CAMHS (Recommandation 7) constituent des exigences minimales pour être **admis dans le réseau.** Comme dans tous les réseaux hétérogènes de dispensateurs, il faut un compromis entre l'appartenance au réseau et la capacité de contrôler la qualité des services.

En bout de course, les systèmes de soutien formels et informels doivent contribuer à renforcer la qualité de vie, les capacités et la confiance des enfants et des parents. Cette démarche étant essentielle pour promouvoir **l'engagement des familles et des jeunes** à contribuer aux services de

santé mentale pour les enfants et adolescents, tant au niveau politique que de la gestion et des services.[17] Le rôle de la famille a été controversé tout au long de ce processus de recherche. Les participants tenaient à reconnaitre que les enfants et leurs familles étaient des parties prenantes importantes, qu'il convient de consulter et d'informer. D'autre part, il n'a pas semblé qu'ils étaient considérés comme des partenaires à part entière pour conceptualiser, amorcer, planifier et dispenser les services de santé mentale. D'aucuns ont avancé que des familles dysfonctionnelles peuvent aussi constituer une cause clé des problèmes de santé mentale de l'enfant.

Recommandation 5

Renforcer la responsabilité pour les enfants souffrant de problèmes de santé mentale graves, multiples et complexes; et développer et consolider la capacité à fournir des soins flexibles et assertifs dans leur milieu de vie.

Le problème et ses causes

Ill s'avère qu'un certain groupe d'enfants et d'adolescents souffrant de problèmes de santé mentale est soit hors d'atteinte, soit ne cadrent pas avec les services traditionnels ambulatoires ou résidentiels. Les parties prenantes les qualifient « **d'oubliés » ou « d'inclassables ».** Un groupe d'étude de l'Institut Wallon de Santé Mentale (IWSM) a estimé qu'environ 3 à 5% des jeunes supportés par l'Aide à la Jeunesse appartiennent à cette population.[22]

De telles situations sont essentiellement le résultat d'un phénomène d'exclusions multiples plutôt que la conséquence d'une 'maladie' particulière. Bon nombre d'entre eux ne recherchent pas de traitement et vont même jusqu'à l'éviter. Ceux qui finissent par être soignés peuvent se montrer non coopératifs. Ces jeunes souffrent souvent de graves problèmes comportementaux. La violence envers eux-mêmes ou autrui figure au nombre des 'symptômes' parmi les plus difficiles à traiter et est souvent à la base de leur renvoi vers un autre niveau de prise en charge. Certains d'entre eux peuvent avoir été placés dans les institutions du système de justice pour mineurs. De surcroît, s'ajoutent aux problèmes précités les goulets d'étranglement dans les institutions de crise et d'urgences (voir la Recommandation 1). « Se renvoyer la balle » est une expression fréquemment utilisée pour décrire la manière dont les institutions de soins/soutiens assurent la prise en charge de ces jeunes. Il s'agit d'une population qui met fortement en relief la fragmentation du paysage des soins de santé mentale pour les enfants et les adolescents.

Pistes de solution

Des études antérieures plaident en faveur de **plateformes performantes dispensant des soins/soutiens mobiles, assertifs, flexibles, multidisciplinaires et organisés en réseau** qui soient en mesure d'atteindre les jeunes souffrant de problèmes complexes dans leur milieu de vie.[11] Il est vital que ces plateformes soient en mesure de préserver la continuité et d'assumer la responsabilité de tout le parcours de soins au niveau des services. A l'échelon institutionnel, elles doivent bénéficier de l'appui de réseaux officiels.

L'étude de la littérature a épinglé le processus de planification de type "Wraparound" (littéralement, « enveloppante » ou « englobante ») en tant qu'approche prometteuse qui occupe également un rôle central dans la démarche des systèmes de soins.[9, 14] L'approche « enveloppante » se caractérise par une palette de services multiples centrés sur l'enfant et définit une stratégie de soins personnalisés et axés sur les forces. Une multitude de services (de crise, thérapeutiques, d'appui aux familles) peuvent être proposés via cette approche « enveloppante ». Un exemple de ce type d'approche mobile et flexible au niveau régional est celle de l'ESPM Lille-Métropole.[9] Dans la région de la métropole lilloise, la demande en soins résidentiels (de même que les listes d'attente) ont été considérablement réduites suite à l'activation d'une équipe mobile à réactivité rapide qui travaille en partenariat avec de multiples acteurs régionaux. L'équipe fait office d'instrument d'appui en cas de crise, de dispensateur de soins assertifs et exerce également une fonction de liaison.[9] Dans ses recommandations, le NRZV/CNEH[13] préconise, pour ce groupe cible, un renforcement des 'soins assertifs', en conjonction avec une prise en charge en cas de crise et d'urgences. Les soins assertifs sont mis en œuvre grâce à une collaboration entre les services de soins résidentiels et ambulatoires et dispensés par une équipe pluridisciplinaire pouvant être épaulée par un pédopsychiatre, le cas échéant.

Éléments à prendre en compte dans la phase de mise en œuvre

Une foule d'initiatives innovantes pour gérer ce groupe cible complexe ont été mises en œuvre, dont 13 équipes de sensibilisation/outreach (établies en Belgique en 2001) sont les plus visibles. Les parties prenantes expriment un avis positif à propos de leur contribution mais elles sont perçues comme manquant d'une masse critique. Un certain nombre de projets pilotes ont également été mis sur les rails en soins médico-legaux (FOR-K[9]). En outre, différents rapports[13, 22, 23] renvoient à des initiatives auxquelles participent diverses coalitions d'aide à la jeunesse, de services sociaux et d'unités spécialisées en santé mentale. Néanmoins, de telles initiatives restent de faible envergure, sont rapidement saturées et constituent un exemple de la manière dont des expériences locales, en l'absence d'une dynamique d'apprentissage et d'une **perspective stratégique,** peuvent contribuer à la fragmentation qu'elles s'efforcent précisément de combattre. Le rapport publié par l'ISWM plaide dès lors en faveur de la mise sur pied de fora transversaux (au niveau méta) dans le but de faciliter ce type d'apprentissage (voir également la Recommandation 7).[22] **La création d'une masse critique de partenariats et de services** pour les enfants souffrant de problèmes complexes confronte manifestement les systèmes de CAHMS à un défi. Les parties prenantes font remarquer que ces types de services sont onéreux et exigent dès lors un financement adéquat. Il est également nécessaire de se doter d'un cadre juridique transparent pour soutenir un travail mobile, flexible et ciblé sur la trajectoire de soins. Les questions déontologiques, les règles financières de même que les questions pratiques d'assurance suscitent des questions (par ex., où tracer la ligne de démarcation entre les soins assertifs et les 'soins contraints'?). En bout de course, cependant, le défi consiste à transcender les divergences profondes entre les différents domaines des soins/soutien dispensés aux adolescents. Il s'agit d'une question de responsabilité et d'éthique professionnelle. Il convient d'avoir des lignes directrices éthiques claires de même qu'un ensemble fort, cohérent et soutenu politiquement d'incitants visant à élargir la capacité en soins mobiles, pérennes et flexibles pour ce groupe cible complexe.

Recommandation 6

Améliorer les compétences culturelles et linguistiques des dispensateurs de soins de santé mentale et des animateurs socio-éducatifs pour les enfants et les adolescents, dans le but de s'adapter aux spécificités culturelles des populations qu'ils servent.

Le problème et ses causes

La **diversité croissante des populations**, surtout dans les zones urbaines, a des implications de taille pour les CAMHS. Si l'influence de l'immigration sur la santé mentale fait débat, c'est indéniable qu'un pourcentage proportionnellement élevé d'enfants de migrants et de réfugiés sont traités dans institutions de protection de l'enfance et de justice pour mineurs.

Pistes de solution

L'objectif global doit être d'offrir un accès aux soins/soutiens accueillant, en travaillant sur l'environnement global du patient et de son entourage, en encourageant le recours aux réseaux et aux dispositifs qui permettent aux professionnels de tenir compte des aspects culturels, ethniques et linguistiques et de garantir que tous les services de soins en santé mentale soient capable d'adapter leurs pratiques pour faciliter l'accès à et l'utilisation des services pour tous les enfants. La promotion des compétences culturelles représente, par exemple, un principe directeur du Systems of Care. Afin d'optimiser le recours aux soutiens naturels et de faciliter la communication entre l'enfant et les professionnels de la santé mentale, la disponibilité en compétences linguistiques et culturelles adaptées est essentielle. **Par compétence linguistique**, nous entendons la capacité de communiquer d'une façon qui soit facilement compréhensible par divers publics. La **compétence culturelle** englobe la faculté d'accepter et de respecter la diversité tout en auto-évaluant sa propre perception des différences culturelles.[14]

Éléments à prendre en compte dans la phase de mise en œuvre

Les professionnels de la santé ne peuvent pas se permettre d'apprendre la langue de chaque minorité qu'ils sont amenés à traiter. D'autre part, les services des interprètes ne garantissent pas un niveau suffisant de compréhension mutuelle entre le professionnel et l'enfant/la famille. Il existe un besoin en médiateurs qui parlent la langue et qui connaissent

également les sensibilités culturelles. En soins de santé mentale, la règle exige que les médiateurs soient **présents physiquement.** Or, l'implication des médiateurs ne pouvant pas toujours être garantie, il est important que les praticiens des CAMHS acquièrent une attitude de sensibilité culturelle. Notamment en cas d'afflux soudain de réfugiés, il doit y avoir une capacité de réaction instantanée car une intervention précoce est cruciale dans de tels cas.

Une attention spécifique doit être accordée à la situation de Bruxelles, non seulement en raison de l'extrême hétérogénéité de sa population, mais aussi de la diversité linguistique de ses institutions et services, qui génèrent des problèmes supplémentaires en termes de coordination et de collaboration entre les acteurs des CAMHS, mais également de cohérence au niveau de la gouvernance.

Recommandation 7

a/ Etablir un dialogue respectueux et multilatéral portant sur une vision partagée du système élargi de soins de santé mentale pour les enfants et les adolescents, en incluant toutes les parties prenantes pertinentes (y compris des représentants des enfants et des familles).

b/ Rédiger une charte éthique destinée à guider les dispensateurs de soins dans la formulation de réponses à la souffrance de l'enfant.

c/ Maintenir et renforcer les forums intersectoriels à différents niveaux institutionnels dans le but d'activer et de mobiliser la collaboration et la formation du réseau sur une base continue.

Le problème et ses causes

Les recommandations du CNEH avancent un certain nombre de principes pour une prise en charge de qualité (good care) – y compris un principe de subsidiarité de même qu'une approche multi-systèmes et basée sur les forces – qui font l'unanimité des auteurs. Néanmoins, les parties prenantes représentées dans le présent travail de recherche ont fréquemment fait référence à des **divergences culturelles et professionnelles persistantes** dans leur approche de leurs missions en qualité de professionnels et de gestionnaires. Ces différences sont accentuées par des facteurs de nature institutionnelle et traditionnelle. Les animosités qui en résultent doivent être reconnues.

Pistes de solution

Des constellations collaboratives et en réseau exigent une base professionnelle et de valeur partagée à partir de laquelle elles pourront fonctionner.[11, 24] Certes, il n'y aura jamais de consensus global, mais un **accord sur les principes et valeurs clés, le respect mutuel et la volonté de concilier les divergences et d'assumer un responsabilité conjointe** peuvent constituer la base d'un cercle vertueux qui mènera à de meilleures issues pour les enfants et les adolescents de même qu'à une pratique plus épanouissante pour les professionnels. Un accord qui est d'autant plus nécessaire que les professionnels de la santé mentale s'opposent, en règle générale, à l'usage de la formalisation et de la standardisation comme mécanismes de coordination.

Une vision partagée des soins de santé mentale pour les enfants et les adolescents joue non seulement un rôle au niveau des services mais aussi du système. Il existe une pléthore d'expériences et de recherches qui confirment l'importance d'une vision partagée pour faciliter les transitions de systèmes.[25]

Les valeurs professionnelles partagées doivent être consolidées dans une **charte éthique.** Ces valeurs représentent une condition nécessaire (sans être suffisante) pour contribuer au bien-être et au développement du jeune. Elles font office de balises pour se positionner par rapport aux intérêts et aux principes qui entourent l'enfant en souffrance. Par ailleurs, de telles valeurs représentent un soutien et un incitant pour les professionnels afin qu'il travaillent de manière créative ('à la marge') dans le respect des contraintes procédurales et institutionnelles, dans l'intérêt de l'enfant. Un engagement de chaque professionnel à incarner ces valeurs dans les soins qu'il dispense aux enfants – avec le soutien de la pratique de l'intervision – consoliderait cette base de valeurs.

Dans le cadre de sa réflexion sur la manière de prendre en charge les enfants souffrant de problèmes de santé mentale complexes, l'ISWM[22] n'a manifestement pas présenté de modèles spécifiques pour organiser des soins mobiles et pluridisciplinaires, mais a plutôt suggéré la **création de fora intersectoriels** ('lieux d'activation et de mobilisation de la transversalité'), à un niveau méta, qui feraient office d'invitation permanente à nouer des relations et à développer de nouveaux partenariats. Les parties prenantes dans ce processus ont proposé

d'organiser ces discussions sur les cas cliniques par mission (patient ambulatoire, prévention, soins résidentiels, etc.), et par groupes de travail transversaux (comprenant un représentant des patients et des familles de même que, si possible et si nécessaire, des personnes possédant des compétences non médicales spécialisées, par exemple, des philosophes).

Éléments à prendre en compte dans la phase de mise en œuvre

Les fora intersectoriels auront pour tâche d'approfondir les principes avancés dans les recommandations du CNEH[13] de même que la définition source émanant de cette recherche. Nous sommes également d'avis que le solide socle de valeurs sur lequel repose l'approche du Systems of Care[14] peut constituer une source d'inspiration supplémentaire. Les parties prenantes reconnaissent que des dialogues doivent avoir lieu. Ils envisagent une 'charte' non pas comme un cadre statique mais plutôt comme un **document vivant** qui s'adapte aux évolutions sociétales et aux besoins évolutifs de l'enfant. La Déclaration des Nations Unies sur les Droits de l'Enfant[c] de même que la Charte Européenne de l'Enfant Hospitalisé (également appelée 'Charte de Leiden[d]) ont été mises en avant comme cadres de référence potentiels. La charte pourrait également être intégrée dans un cadre d'amélioration continue de la qualité.

Du point de vue du niveau du service, il est logique de calibrer les fora intersectoriels **à l'aune du 'bassin des soins',** compte tenu du fait que les caractéristiques partagées d'un territoire jouent un rôle au niveau de la facilité avec laquelle les réseaux fonctionnels se forment. Néanmoins, du point de vue des systèmes, il est très certainement recommandé d'avoir une **assemblée générale** à l'échelon régional ou national. L'autorité du forum doit être assise par le truchement d'un système de financement à contribution mixte (braided funding) impliquant des partenaires du secteur des soins de santé mentale, d'aide à la jeunesse, des soins aux moins valides et autres.

Recommandation 8

Obtenir de bonnes données qualitatives et quantitatives sur les besoins en et l'offre de services en santé mentale pour les enfants et les adolescents, pour potentialiser de façon efficace les établissements de soins répartis au niveau régional et afin de faciliter la formation de réseaux de soins régionaux.

Le problème et ses causes

Les politiques, les gestionnaires des soins de santé et les professionnels de la santé se trouvent à la barre d'un système de CAMHS complexe. Un défi clé lié à la planification consiste à obtenir des données de bonne qualité à propos du type et de la fréquence de la demande à laquelle se trouve confronté le système de soins. En Belgique, abstraction faite des chiffres relatifs à la prévalence générale, ce type d'**informations fait pratiquement défaut**. Les parties prenantes évoquent de longues listes d'attente pour avoir accès aux services tout en étant bien conscientes du fait que ces chiffres sont sans doute gonflés et ne représentent pas la réalité. Dans le même ordre d'idées, la taille des populations cibles spécifiques est souvent inconnue. Les données des institutions individuelles sont à peine, voire pas du tout consolidées au niveau régional ou national.

Outre la demande, se pose le défi de comprendre quels sont les **besoins réels** des enfants et des familles, par opposition à d'autres besoins qui ne sont pas nécessairement le mieux satisfaits par des soins de santé mentale spécialisés. Dans la société, on observe une tendance à médicaliser trop rapidement des problèmes psychosociaux relativement courants.

Si la demande et les besoins restent fréquemment non quantifiés, c'est également le cas pour **l'offre.** Les parties prenantes ont souligné à quel point il est difficile de tenir à jour la liste de toutes les infrastructures disponibles dans le système de CAMHS fragmenté et à composantes multiples.

c http://www.unicef.org/crc/

d http://www.each-for-sick-children.org/each-charter

Pistes de solution

Si nous voulons calibrer la capacité des services de soins répartis au niveau régional, nous devons en savoir davantage à propos de la demande réelle (à savoir, la demande pour laquelle le service existe et est sensé répondre) et la demande évitable (une demande provoquée par le manquement de réponses correctes aux besoins du patient).[26]

La justification de la demande pour **davantage de services de soutien et d'émancipation pour les enfants et les familles** (Recommandation 4) réside en partie dans le renforcement de leur capacité à jouer un rôle actif dans l'évaluation et l'organisation de leurs besoins, afin de faire contrepoids avec la charge des routines et protocoles fixes. En outre, il a été établi qu'une évaluation conjointe des besoins des enfants facilite la mise en commun d'informations de même que l'intégration des services entre les différents secteurs et agences qui servent cette population (voir le Cadre Commun d'Evaluation au Royaume Unis).[9]

Afin de faciliter la formation de réseaux (inter-)sectoriels, on préconise de dresser la **cartographie des services et capacités disponibles au niveau régional ou du 'bassin de soins'.** Le modèle d'activités et la cartographie des parties prenantes que contient la présente étude constituent un modèle général potentiel à cette fin. Les Réseaux des Dentres d'Expertise flamands (SEN) constituent un premier exemple de ce principe. Ces réseaux sont financés par la VAPH (Agence Flamande pour les Personnes souffrant d'un Handicap) qui cartographie les services et capacités disponibles au niveau des provinces dans le domaine de l'autisme (voir le rapport du KCE, partie 1, page 66). Une fois de plus, nous nous référons également au RU, où une cartographie des services pédiatriques a existé jusqu'en 2010.[9]

Éléments à prendre en compte dans la phase de mise en œuvre

Certaines parties prenantes émettent des doutes quant à la possibilité, voire l'utilité de cartographier la demande en soins de santé mentale et proposent de se fier aux données internationales pour combler les lacunes.

Recommandation 9

Appliquer et définir des méthodes d'évaluation fondées sur les meilleures pratiques internationales, qui reflètent les spécificités nationales ou régionales, et en accord avec les orientations éthiques, dans le but de renforcer la responsabilité, l'amélioration de la qualité et la multidisciplinarité au sein de la dispensation de soins de santé mentale pour enfants et adolescents.

Le problème et ses causes

Le recours aux méthodes d'évaluation dans les CAMHS est **controversé**. Les professionnels se sont exprimés sans détour dans le cadre de ce processus de recherche participative à propos de leur expérience frustrante de ces dernières années avec les méthodes d'évaluation dictées par la politique. Le RPM/MPG en particulier, est mis en avant comme étant lourd et sans intérêt. En outre, ils redoutent que les cadres d'évaluation brident ou soient en conflit avec la flexibilité thérapeutique. Or, cette dernière est revendiquée comme étant indispensable, compte tenu du large éventail de problèmes de santé mentale auxquels ils se trouvent confrontés, de même que de la spécificité des besoins des enfants qui changent au fil de la trajectoire de développement. On reconnaît néanmoins qu'au niveau du système, la gestion des CAMHS est entravée par le fait qu'il **n'existe pas d'évaluation de son efficacité globale.** En outre, au niveau des services, il est malaisé de documenter l'amélioration (continue) de la qualité, faute de méthodes d'évaluation idoines (voir également le rapport du KCE 146).[11]

Pistes de solution

Dans d'autres pays, diverses initiatives ont été entreprises. AU RU, le consortium de recherche CORC, auquel sont affiliés la moitié de tous les services en Angleterre, est en passe d'élaborer un **modèle commun d'évaluation régulière des résultats.** A l'heure actuelle, cinq instruments de mesure des résultats scientifiquement validés sont utilisés en routine (par ex., HoNOSCA: Health of the Nation Outcome Scales for Children and Adolescents) sur une base volontaire.[9]

Éléments à prendre en compte dans la phase de mise en œuvre

Les parties prenantes ont suggéré un certain nombre de **caractéristiques importantes** des méthodes d'évaluation:

- L'évaluation doit être soucieuse de la complexité inhérente à la dispense des soins aux enfants et adolescents souffrant de problèmes de santé mentale et de développer plutôt que de restreindre le répertoire thérapeutique des dispensateurs de soins;
- L'évaluation doit s'inspirer des meilleures pratiques internationales, tout en étant dans tous les cas adaptée aux circonstances nationales, régionales ou locales;
- Elles doivent respecter les balises éthiques (Recommandation 7);
- L'évaluation ne peut se concrétiser que lorsqu'il y a un véritable sentiment d'appropriation dans le chef de toutes les parties prenantes. D'où la nécessité de les impliquer dans la conception du processus d'évaluation et de sa finalité de même que dans l'interprétation des résultats (voir également Pires[17]).

Les préoccupations des parties prenantes à propos de l'indispensable flexibilité des méthodes d'évaluation sont à l'unisson par rapport aux évolutions internationales récentes, telles que 'Utilization-focused Developmental Evaluation'[27] et Reflexive Monitoring.[28] Il s'agit de cadres adaptifs qui ont été élaborés pour les environnements complexes et dynamiques dans lesquels il est nécessaire d'innover et d'expérimenter en permanence. Nous sommes d'avis que ce type de cadre est en très bonne adéquation avec l'évaluation sensible à la complexité, guidée par l'éthique, participative et situationnelle qu'exige la communauté des CAMHS. La présente Recommandation s'articule avec tous les aspects de la Recommandation 7 et avec la Recommandation 8.

Recommandation 10

Donner un signal politique clair qui encourage et récompense un climat innovateur dans le système belge des CAMHS, et rendre cela tangible par la mise en place rapide d'initiatives concrètes d'exécution.

Les professionnels de la santé mentale qui ont participé au présent projet sont désireux de dépasser le stade des discussions et de se mettre concrètement en quête d'une manière d'aller de l'avant vers un 'meilleur' système de santé mentale pour les jeunes. Un signal politique clair selon lequel on encourage et on récompense une culture de l'innovation dans le système des CAMHS belge est requis. Les 9 Recommandations discutées ci-dessus peuvent être assimilées à un agenda de l'innovation destiné à orienter les efforts sur le terrain.

Compte tenu de l'absence à court terme de budgets importants pour soutenir la réforme des CAMHS, il convient d'adopter une approche pragmatique, positive et génératrice de confiance.

1. La **promotion et la reconnaissance de l'innovation de type 'bottom-up' (du bas vers le haut)**

   Au RU, le 'National Health Service (NHS) Institute for Innovation and Improvement' a institué un programme intitulé 'NHS Innovation Challenge Prizes' (qui en est à sa deuxième année)[e]. Ce Challenge Programme' a pour but d'identifier les innovations prouvants pouvoir répondre à des défis spécifiques, et conçues de telle sorte qu'elle puissent facilement être propagées dans l'ensemble du NHS. Les lauréats de ces récompenses peuvent recevoir jusqu'à 100.000 GBP. L'agenda plus vaste derrière cet effort du NHS en faveur de l'innovation consiste à améliorer considérablement l'efficacité du NHS au cours des quelques prochaines années afin de relever les défis inhérents à une demande croissante pour des services de qualités et une amélioration des résultats pour les patients.

   Cette promotion et cette reconnaissance de l'innovation de type 'bottom-up' constituent un principe qui mérite d'être transposé dans le contexte belge des CAMHS. Une telle transposition nécessiterait un

[e] http://www.challengeprizes.institute.nhs.uk

cofinancement par le gouvernement fédéral et les autorités fédérées afin d'encourager les partenariats intersectoriels.

2. Le **développement d'un plan d'action complet et de projets d'innovation concrets**

   Il est absolument impératif que l'innovation 'bottom-up' soit en mesure de se répandre et de s'intégrer dans le système de soins au sens large. La reconnaissance et la récompense constituent un premier pas sur cette voie. Cependant, le NHS a mis en place un plan d'action complet, opérationnel depuis début 2012, pour garantir que les innovations et les meilleures pratiques ne restent pas des exemples isolés mais soient bénéfiques pour l'ensemble du NHS.[29] Si elles étaient transposées dans la situation belge, la Conférence Interministérielle de la Santé pourrait commanditer une taskforce ayant pour mission de traduire un certain nombre des Recommandations du présent rapport en un plan d'action concret, définissant une série de projets d'innovation spécifiques. Un appui pourrait être recherché auprès de la Fondation Roi Baudouin (Fonds Reine Fabiola pour la santé mentale)[f].

   A un niveau intermédiaire, les plateformes intersectorielles de gestion et de responsabilisation préconisées dans la Recommandation 7 représentent un point nodal au niveau duquel les dynamiques 'bottom-up' et 'top-down' peuvent nouer un maillage et se renforcer mutuellement via le développement de plans stratégiques locaux, d'accords inter-agences, de propositions législatives, d'accords de financement et de protocoles de suivi et d'évaluation adéquats.

3. Idéalement, une **infrastructure d'appui doit être mise en place** pour aider les professionnels à accroître leurs compétences pour améliorer leurs services par le biais d'un coaching et d'une formation à l'utilisation des outils d'amélioration novateurs. Au RU, par exemple, on met énormément l'accent sur les méthodes récentes de conception basée sur les services et l'expérience.[g]

[f] http://www.kbs-frb.be/fund.aspx?id=191556&LangType=2067

[g] http://www.institute.nhs.uk/innovation/innovation/introduction.html

6. CONCLUSION

Ce présent projet de recherche participative a offert aux parties prenantes l'opportunité de réfléchir à l'orientation que devrait prendre une réforme du système des CAMHS. Une **analyse diagnostique** a révélé que le système des CAMHS se trouve aux prises avec un ensemble de problèmes interdépendants, le principal écueil se situant au niveau de la fragmentation et du cloisonnement extrêmes entre les organisations, secteurs, professions et piliers confessionnels. Le cout d'une telle fragmentation est considérable, tant en termes de souffrance humaine que de gaspillage de ressources. Les très longues listes d'attente ne représentent que l'un des indicateurs parmi les plus évidents de ces charges et inefficacités. Les parties prenantes reconnaissent cette situation.

Au cours de la dernière décennie, plusieurs initiatives ont été entreprises au niveau du système et des services pour remédier à ces pressions. Toutefois, ces innovations n'ont pas été en mesure de renforcer la capacité d'adaptation du système dans son ensemble. Les échecs du passé ont suscité une méfiance entre les acteurs et les secteurs.

Les parties prenantes ont affiché une vive résistance par rapport à une formalisation et à une maîtrise de type top-down. Avec pour résultat qu'autant les professionnels se rendent compte qu'une manière de travailler en plus étroite collaboration et en réseau est indispensable, qu'ils ont peu confiance en une officialisation de ces réseaux et en la création de nouvelles fonctions, notamment celles de gestionnaires et coordonnateurs de réseau.

L'ensemble des considérations qui précèdent mènent à une situation de blocage (lock-in) pour laquelle on ne peut escompter de solution rapide. Le processus de changement sera très probablement de longue haleine et la présente étude ne constitue qu'un petit pas dans ce cheminement.

S'agissant des CAMHS, la pertinence du **cadre offert par le Systems of Care a été mise en exergue.** Ce cadre est apparenté au domaine plus vaste de l'innovation des systèmes. De telles approches recherchent en général un alignement, une coévolution entre le changement de type 'top down' et 'bottom up' afin d'éviter les pièges soit d'un changement fragmentaire, communauté par communauté, soit d'une réforme

technocratique globale. La présente recherche s'inscrit dans un esprit similaire, sans toutefois adhérer servilement à un seul modèle, quel qu'il soit.

L'exercice de regroupement de tous les constats des divers piliers de cette étude nous amènent à formuler 10 Recommandations:

Les recommandations 1 à 4 ont pour vocation, conjointement, **d'organiser les exigences demandées aux rares et onéreux services spécialisés de santé mentale** pour les enfants et les adolescents. Le but est de faire en sorte que les jeunes reçoivent des soins adéquats dans l'environnement à la fois le moins restrictif et le mieux adapté possible. On attend d'une telle approche qu'elle aboutisse à un recours plus avisé aux soins spécialisés et aux infrastructures résidentielles. Les recommandations veulent atteindre cet objectif via la *prévention*, *l'émancipation* des utilisateurs et de leur entourage (familles), *un filtrage adéquat* au niveau des soins de première ligne et en renforçant la capacité du système à gérer les *situations de crise liées à la santé mentale.*

Les recommandations 5 et 6 se concentrent sur un **renforcement de la gamme de services offerte par les professionnels de la santé mentale, notamment s'agissant des soins aux enfants souffrant de problèmes de santé mentale graves, complexes et multiples**. Ces situations complexes peuvent ou pas être associées à un comportement violent ou à des barrières culturelles. Les recommandations veulent remédier aux défaillances de responsabilité (passer 'le problème' à quelqu'un d'autre) lors de la prise en charge de ces jeunes, en *renforçant une approche souple et assertive* pour dispenser des soins à ces enfants dans leur milieu de vie et en *améliorant les compétentes culturelles* des dispensateurs de soins.

Les recommandations 7 à 9 ciblent un **renforcement de la capacité d'adaptation et de la guidance éthique dans le cadre du futur système des CAMHS**. Elles entendent concrétiser cet objectif en s'assurant que les acteurs du système, y compris les représentants des enfants et de leurs familles (entourage), participent à des forums inter-sectoriels afin de stimuler des partenariats sur une base continue. Elles proposent que toutes les parties prenantes s'engagent à développer une *vision partagée* et une *charte éthique* pour le système des CAMHS au sens large. Elles préconisent également de déployer des efforts continus pour *mieux comprendre les besoins et la provision de services de soins de santé mentale.* Enfin, une recommandation concerne les *méthodes d'évaluation* qui renforcent le professionalisme, la qualité et la multidisciplinarité.

La recommandation 10 propose des **démarches à entreprendre par la suite.**

Par opposition aux solutions fragmentaires ou de type top-down, qui sont souvent inspirées de manière disproportionnée par les groupes de pression, la présente recherche met l'accent sur la nécessité d'apporter des **« changements au niveau du système »** afin de soutenir les modifications en termes de provision de services. En nous inspirant des enseignements tirés de "l'innovation des systèmes" et de "la gestion de la transition", nous mettons en garde contre une perception qui y verrait les manifestations d'une théorie de changement linéaire: d'abord, il faut améliorer les systèmes, ensuite les services et enfin les résultats.

Certes, des changements au niveau du système sont vitaux pour soutenir la transition vers un système de CAMHS plus performant. Effectivement, la présente recherche a montré comment des innovations isolées au niveau des services, quoique bien intentionnées et magistralement mises en œuvre, risquent à un certain stade d'accroître encore la fragmentation du système. D'autre part, il est important de continuer à encourager une expérimentation au niveau local et à contribuer à la concrétisation de réussites, en particulier lorsqu'elles sont le fruit de partenariats intersectoriels ou intra-sectoriels. Le savoir et le capital relationnel engrangés grâce à de telles collaborations constituent le substrat pour une transformation à l'échelle de l'ensemble du système. Les dynamiques 'bottom-up' et 'top-down' doivent se renforcer mutuellement.

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SCIENTIFIC REPORT

1. INTRODUCTION

Internationally, the World Health Organization (WHO) has called for national address of child and adolescent mental health concerns.[1, 2] Belgium, however, does not have an articulated child and adolescent mental health strategy. Reforms in the past have, as in other Western countries, focused on the adult mental health sector. This sector previously characterised by large isolated institutions, is gradually transformed towards a balanced care model. This implies that care is offered and delivered as close as possible to the patient's living environment, and only if necessary in an institution.[3]

The child and adolescent mental health services (CAMHS)-sector is different and requires a different approach. Firstly, mental health problems in children and adolescents are not uncommon. Based on studies that used a validated questionnaire, the WHO 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.[9]

Secondly, the WHO states that there is a high degree of continuity between child and adolescent disorders and those in adulthood.[2] The WHO estimates that roughly 50% of mental disorders in adults begin before the age of 14 years.[6] Therefore, it is argued that appropriate interventions in child and adolescence can greatly enhance population health while improving outcomes for the young people involved.

Thirdly, it is widely adopted that designing an appropriate mental health policy for children and adolescents should include a developmental perspective. The different consecutive developmental stages that children and adolescents go through have an impact on vulnerability to disorders, how the disorder is expressed and should be treated).[7, 8]

Finally, the CAMHS-sector on Belgium developed much later than that for adults and does not have a tradition of large isolated inpatient service institutions.

In Belgium two initiatives were launched in close succession to support reforms in child and adolescent mental health services (CAMHS). Both were commissioned by the Ministry of Social Affairs and Public Health. The

first initiative concerns an advice by the National council of hospital facilities[13] to the Minister of Social affairs and Public Health. This advice, published on June 9th 2011, points out the actual problems and the future needs in the sector of child and adolescent mental health care in Belgium[h]. It is based on a broad consultation of stakeholders working in the domain of CAMHS (child and adolescent mental health services). This important document has been of considerable help in this study, and our conclusions and recommendations will, whenever appropriate, be articulated with this advice. A **second initiative** is the present KCE-study which was commissioned by the Federal public service for health, food chain safety and environment. The study includes two parts. The first part, evaluated existing scientific knowledge in the area of organization of CAMHS by conducting a narrative literature review and an analysis of recent reforms in British Columbia (Canada); the Netherlands, the UK and France.[9] The two main models found in the literature (i.e. WHO-model and 'System of Care') 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. 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.[9] The literature and the international overview therefore only offer us a limited basis in the search for a better organizational structure for the child and adolescent mental health care sector.

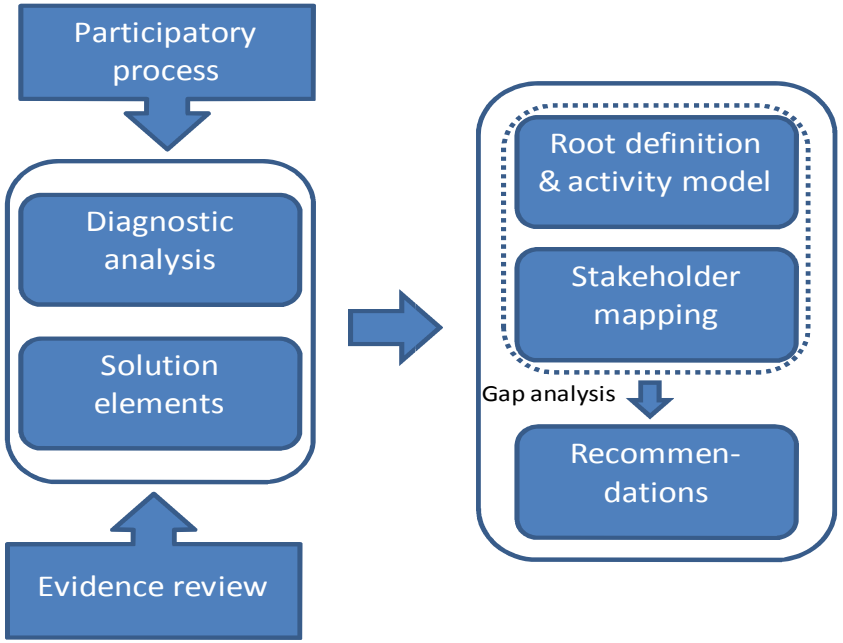
The second part of this KCE-study, which is the subject of this report, will build on this (limited) evidence base. However, the data from the literature and the examples from other countries do in fact have to be interpreted in light of the specific Belgian context. The **objective of the current research project** is, therefore, to develop a scenario for the organization of mental health care for children and adolescents in Belgium based on a method of stakeholder participation.

h http://www.health.fgov.be ; http://www.overlegplatformsggz.be/Adviezen_NRZV/284/ggz

2. METHODS

This section of the report describes the methods and techniques employed to develop a scenario for the Belgian CAMHS system. First the overall logic of scenario development and the tools used to conceptualize it are clarified. Then the constituent elements of the participatory process are discussed. Finally, there is a note on the evidence base relied on during this research, and on the limitations of the methodology used in this report.

Figure 1: Conceptual outline of research process



2.1. Scenario development

2.1.1. Introduction

In the setting of this particular study, the aspect that concerns us is an institutional and organizational reality: the way mental health services for children and adolescents will be organized and delivered in Belgium. We therefore see a 'scenario' as a policy scenario, meaning a description – a qualitative 'model' - of a future service system (defined as "a configuration of technology and organizational networks designed to deliver services that satisfy the needs, wants, or aspirations of customers"[i]). Such a model will be a mix of narrative elements and visual representations (diagrams) that explains the functional logic of that envisaged service system and makes reference to relevant formal and informal actors, and connections between these actors (through formal agreements and all kinds of flows, such as finances, people and information). The task is, therefore, to describe, using textual and visual means, how future mental health services for a specific target group will be organized. The basic purpose of this description is to provide policy makers with guidelines for system reform.

The study relies on two main lines of enquiry: a participatory process to solicit input from a range of stakeholders, and an evidence review. Both lines of enquiry will feed two main areas of attention. First, a diagnostic analysis to understand what are strengths in the existing CAMHS system and what could be improved. Second, a series of solution elements that could be integrated in a future, more effective system. The diagnostic and solution elements are used to develop two sets of outputs. On the one hand a number of visual, conceptual models are developed that delineate the contours of the future children and adolescent mental health care system.

The aim of these models is not to give a final picture of what the future CAMHS system will look like but to lay down the contours of that system to be given substance by carefully designed interventions in the existing system. This set of recommendations for intervention in the CAMHS system, based on the diagnostic and solution elements identified, is the other output generated by this study. The logic is diagrammatically shown in Figure 1.

2.1.2. Conceptual modeling

In developing conceptual models that lay down the contours of a future CAMHS system, the approach adopted in this research is inspired by Soft Systems Methodology.[30-32] Soft systems methodology is one of a range of general, systemic problem solving approaches.[33] The purpose of Soft systems methodology is basically to organise a process of 'learning for action'[12] the aim of which is to intervene in an 'organisational setting' in order to improve it. Distinctive for the Soft systems approach is the fact that it tends to anchor a process of change in what is (cultural and managerial) feasible for those participating in it. Other approaches, such as Interactive Planning for instance, are oriented towards identifying more visionary (but also more long-term) interventions. For the present study the focus on pragmatism and feasibility was deemed more appropriate. Another potentially strong point of the Soft systems approach is the fact that it is designed to reflect the different framings (or worldviews) that stakeholders rely on in making sense of a complex problem in multiple scenarios. The methodology then allows to identify a single way forward by seeking accommodation between these different scenarios. The possibility of the emerging of different scenarios from the research process has been anticipated from the very start of the research process. However, as the process unfolded it became clear that one single scenario was able to capture the issues identified by the stakeholders.

The Soft systems methodology makes use of conceptual representations (or scenarios) for systems to guide the efforts to streamline or re-design the system under study. The basic orientation of the methodology, therefore, fits hand in glove with the basic aim of the study. The elements drawn from Soft systems methodology are a diagnostic Rich Picture, a Root Definition, and an Activity Model. In this study this set of tools has been complemented by a Stakeholder Mapping. Each of these instruments will be discussed in turn.

[i] http://en.wikipedia.org/wiki/Service_system

Rich Picture

A rich picture is a visual aid to learn about ill-defined problems by drawing detailed ("rich") representations of them. Its orientation is diagnostic as it makes explicit the perceived structure of a problem. Typically, rich pictures follow no fixed syntax, beyond consisting of pictorial elements and text, and can be drawn by hand or by means of more specialized tools.[34] In this particular case, the rich picture has been developed as a so-called 'influence diagram', which relies on a simple visual syntax of 'factors' and arrows that denote interlinkages between factors.[35]

Root Definition

A root definition is a textual description of the unique contribution (the 'purpose') that the system is meant to deliver.

Typically, in a soft systems approach the 'system' considered is not an organizational entity with a recognized boundary, legal status, resources, power and so on. Instead, it is a notional or an idealized system. This has also been referred to as a 'work system' or a 'human activity system'.[36] A work system consists of people jointly engaged in recognizable activities to realize a shared purpose. These people can easily belong to different formal organizations. Once it is clear what the purpose of the 'work system' is and what the requisite activities are to support it, one can start to inquire how people, potentially from different organizations, can contribute to the work system in order to realize its purpose.

The essence of a system in Soft Systems Methodology is captured by a root definition.

A root definition is a precise statement that takes the following generic form: "A system owned by O and operated by A, to do X by Y to customers C in order to achieve Z within constraints E"[31]

Activity Model

The root definition expresses what the human activity system under study is intended to do. It is the basis for developing an activity model that shows how the system will realise its purpose.

An activity model is a notional model. It does not represent an actual, existing system but it is a conceptual representation of an idealized system that is able to deliver that unique contribution as encapsulated by the root definition. It consists of 'activities' and logical dependencies between those activities.

This instrument considers key functionalities and their interdependencies without becoming sidetracked by the complexity of the existing CAMHS landscape. It does not embody an organizational logic, but a functional one.

Stakeholder Mapping

A stakeholder map is a visual representation of how actors that have a role, interest or stake in a particular system (or problem) relate to that system.[37] Various formats are in use. In this study a format was developed that arranges the stakeholders in concentric circles around the child (suffering from psychosocial or mental problems). The distance to the child and the relative positioning of the actors to one another are significant features of the map. Four types of relationships between actors are visually codified: collaborating, funding, caring, and defending interests. In contrast with the activity model which represents a notional model, the stakeholder map reflects how the actual CAMHS system is perceived. However, once the map is linked to the activity model - by visually coding into the map the activities (from the model) where actors might potentially contribute to – it assumes a hybrid character and becomes in fact a pendant to the activity model.

2.1.3. Gap analysis and recommendations

Policy recommendations are a second key output from this study. These are suggestions for interventions in the current CAMHS system with the aim to help it transition to a system that works 'better'. They are informed by a number of inputs:

- The diagnostic elements highlight a number of key service and system-level problem areas in the Belgian CAMHS system. Recommendations need to address those challenges.
- The participatory process and the literature review (see section 2.2 and 2.3) point towards a number of potential solution elements that may be integrated into the recommendations.
- The conceptual modeling will highlight key characteristics of a future, desirable CAMHS system. The recommendations will have to be in alignment with these characteristics.

- In addition, analytic frameworks from relevant areas of expertise (medical sociology, system innovation and systems thinking) offer insights that can be used to shape policy recommendations.

The identification of these policy recommendations in effect results from a 'gap analysis' between the existing CAMHS system and a desirable future system.

The goal is to end up with a limited set of recommendations that could be taken forward by policy makers and stakeholders in the field.

2.2. Participatory process

2.2.1. Participation events

The stakeholder engagement is organized around five participation events:

- An **exploratory round of interviews** (July – September 2011) to explore stakeholder views on the current problems and bottlenecks in the CAMHS system and elements of a future, more effective system. In giving access to first-hand information on current and future issues in the CAMHS system the interviews complement the unfolding evidence review (see section 2.3). But they also fit in what Checkland and Poulter[12] refer to as Analysis Three in a Soft Systems-driven process. Analysis Three focuses on understanding the disposition of power in a situation and how that affects what is 'culturally feasible' in a change process. Finally, the interviews offered an opportunity for these key people to develop confidence in the participatory process.
- An **initial roundtable discussion** (focus group) with professionals, experts, patient representatives and administrators, to give input to the process of conceptual modelling (14 September and 16 September 2011 for the French and Dutch-speaking groups respectively).
- A **validation workshop** to discuss and improve the emerging root definition and activity model (18 October and 20 October 2011 for Dutch and French-speaking groups respectively). The audience for the validation workshop is also primarily geared towards expert, professional and institutional representatives, and patient representatives.
- A **consultation round of interviews** (mid-November 2011-early January 2012) the aim of which was to give certain influential stakeholders a better opportunity to voice their opinions, to elucidate some of the points that had come up in the validation workshop and to include a number of complementary perspectives, particularly from professionals in other youth-serving sectors than CAMHS.
- A **consolidation workshop**, again for a similar audience, to discuss the draft policy recommendations (16 and 17 January 2012 for French and Dutch-speaking groups respectively).

The process of stakeholder participation is organised for a French-speaking and a Dutch-speaking stakeholder group separately. The motivation to split up the process in two language-based tracks is both practical and technical. Even with the support of translation services it is hard to implicate different language groups at the same time in a technical, very interactive process. Furthermore, the language differences also signify considerable institutional and therapeutic differences in mental health care. Integration of Dutch and French speaking groups in a shared participatory process potentially confounds these differences.

The five engagement moments are discussed in more detail in Table 1. A general comment as regards the orientation of these events is in order. The purpose of the interviews, roundtables and workshops is to work with the input from stakeholders. At no point during the process it is the intention to shape or validate stakeholder perceptions by external (scientific) evidence (obviously stakeholders were at liberty to substantiate their views with evidence, which they often enough did). The confrontation between stakeholder perceptions, research insights and other sources (such as the Advice of the National council for hospital facilities) is left to the argumentation supporting the recommendations in this report (Section 5). Whenever the participation events are discussed, the reader of this report should be aware of the fact that the statements are stakeholder views and not necessarily proven facts.

In addition, one member of the research team was embedded for 2, 5 days at the Karibu unit at the CHJ Titeca hospital in Brussels. This was the first of 5 residential forensic psychiatric pilots created by the Belgian government in 2003 for young offenders with both psychiatric and behavioral problems who require educational and social protectionist

measures. The unit receives 14 adolescents between 14 and 18 years old. The purpose of the observation was primarily to get a firsthand experience of the complexities associated to making an innovative therapeutic approach work, one that is attempting to place the concept of "good-care" at the center of mandatory aid as an ethical foundation. A report of the observation stay is in Appendix 1.

Table 1: Stakeholder engagement process

	Rationale	Questions	Format	Participants
Exploration round interviews	To explore stakeholder views on the current CAMHS system; To get a feel for the disposition of power and what change is 'culturally feasible'.	• What are the key problems with the current CAMHS system? What works well? What would you do to improve the functioning of the system?	Face-to-face interviews	5 FR and 5 NL stakeholders and administrators from CAMHS and other child-serving sectors
Roundtables	To make explicit stakeholders' perception of the existing CAMHS system, to highlight relevant interventions for a future system; To create interest and confidence in the value of the study	• What are essential characteristics of the existing CAMHS system? • What is the basic purpose of a future, improved CAMHS system? • What interventions would help in moving towards a more efficient and effective mental health care system for children and adolescents in Belgium?	Focus group[38]	Cross-section of 15-20 stakeholders targeting per language group
Validation Workshop	To validate the emerging root definition and activity model (scenario) for CAMHS	What are stakeholders' opinions about the emerging root definition and activity model? How can they be improved?	Custom-designed ½ day workshop (Agenda: Appendix 2)	Cross-section of 12-20 stakeholders per language group
Consultation round interviews	To deepen insights from the validation workshops; To give stakeholders who had not been heard an opportunity to express themselves in depth.	What would a value base underlying a CAMHS system entail? How can a network-based approach be put into practice? How to improve the effectiveness of the access gate to the CAMHS system?	Face-to-face interviews	9 FR and 9 NL stakeholders from CAMHS and other child-serving sectors
Consolidation workshop	To reflect on and improve the final draft of policy recommendations	How can these recommendations be better formulated? What possibilities do you see to operationalize them? What obstacles may exist in realizing them?	Custom-designed ½ day workshop (Agenda: Appendix 2)	Cross-section of 15-20 stakeholders per language group

2.2.2. *Identification and selection of stakeholders*

In this study stakeholder engagement focuses on **professional, expert and institutional stakeholders**. Children and adolescent users/patients are therefore not directly implicated in the process. The user perspective is included in the process by way of representatives of parents and/or patient organisations and self help groups. The absence of young people with mental health problems themselves is a limitation of the study. The motivation not to include them in the stakeholder group was to a significant extent linked to the time constraints of the current study in conjunction with the technical nature of the discussions[39]. It is possible to give young people with mental health challenges a voice in consultative processes[40] but the experience of the project team was that this requires sufficient time and empathy. In absence of these conditions consultation might even prove to be counterproductive.[40] Another element that compounded the time constraint is the absence in Belgium of a strong advocacy and self-help organization for specifically this target group. This would make recruitment a much more lengthy and tortuous process, something that could not be envisaged within the time frame available for the study.

Based on Part I of this study[9] and on the input from the interviews it was decided to invite people from the child and adolescent mental health services and from **other youth-serving sectors** (education, juvenile justice, youth care) as well. Professionals from the adult mental health sector were, on the other hand, not invited to the stakeholder group (although, in principle, they might have contributed in understanding the difficulties of young people transitioning into the adult system). Desk research and punctual information collected from key informants from our existing network were used to **compile a long list** of relevant CAMHS stakeholders. The 1st draft of the long list was screened using profile criteria (i.e. Practitioner, NGO, admin and Geographic distribution).

- Practitioners: including private and public sector, child psychiatrists (both biomedical and social orientation represented), child psychologists (both neuropsychologist and psychotherapist) , juvenile justice lawyers or judge, paediatricians and other health practitioners, school professionals and youth justice professionals);
- NGO: patients / children, adolescents and family rights advocate;
- Administrators: managerial functions in public/private institutions (including government agencies, public hospitals, schools, organisation like Zorgnet[j] etc.).

Roundtables and workshops

Out of this list, people were invited for the different stakeholder events. The selection was based on two criteria. First, it was aimed to have 15-20 participants in each language group. Second, it was aimed to have a mix of profiles. An overview of participant profiles for the three interactive participation events (roundtables and workshops) is shown in Table 2.

A relatively high number of child and adolescent psychiatrists participated in the workshops as compared to other clinicians and stakeholders. This was partly a result of the selection process, which was aimed at involving a sufficient number of child psychiatrists in view of their expertise, authority and the pivotal role they play in the current system. On the other hand, it has to be said that a high number of child psychiatrists accepted our invitation to the various workshops, in which they played a very active role. Thus, a certain bias towards the perspective of child psychiatrists must be taken into account.

Some participants fit into various categories, e.g. a clinical psychologist who is also director of an ambulatory mental health service. In these cases, the second function is indicated between brackets.

In some categories, the participation rate was slightly lower than targeted. This was mostly due to late cancellations or non-appearances.

[j] www.zorgnetvlaanderen.be

Table 2: Stakeholder profiles in interactive participation events

Stakeholders	Roundtables		Validation workshops		Consolidation workshops	
	NL 16/09/2011	FR 14/09/2011	NL 18/10/2011	FR 20/10/2011	NL 17/01/2012	FR 16/01/2012
Child psychiatrists	3	7	7	9	6	**5**
Psychologists	1	1	3	3	2	**3**
General practitioners	1	1	1	1		**1 + (1)**
Paediatrician	1	1				
Ambulatory: CGG/SSM/AIGS	(1)		(2)	3	1 + (1)	**2**
Juvenile Justice		1	1	1		**1 + (1)**
Education		1		1		**1**
Youth Care			1		1	
Patient/Child/Family rights	1	1	2	1	2	**1**
Network coordination			1 + (1)	(4)		**1**
Prevention	(1)	(3)				**(2)**
Administration (federal)	2	2	2	1	2	
Administration (Community/regional)	3	(3)	1	(2)	1	**(3)**
Disability care		1		1		**1**
Social profit employers organisation			1		1	
Scientific institutions	1+(3)	1 + (3)	(6)	2 + (4)	1	**1 + (5)**
Total	13	17	20	23	17	**17**
Target	**12**	**12**	**20**	**20**	**20**	**20**

Interviews

For the exploration round interviews and consultation round interviews people were chosen because of their assumed influence in the stakeholder field and/or their contributions at the validation workshop.

The exploration round focused on a small sample of 10 key stakeholders (5 French-speaking and 5 Dutch-speaking). In addition, the written input of one additional stakeholder, submitted as an alternative for a face-to-face was included as well.

These stakeholders are individuals that have considerable political influence or they are experts/professionals that are known to have a very outspoken view on the organization of the CAMHS system and are likely to have an important influence on their peers (opinion leaders). They were selected from the long list of candidate participants (see section 2.2.2).

The consultation round followed up on the validation workshops (section 2.2.1.). Altogether 18 interviews – 9 FR and 9 NL - were done between mid-November 2011 and early January 2012. Representatives from specialized mental health services were 7 child psychiatrists (5 FR, 3 NL, all affiliated to psychiatric hospitals), and a director of a child psychiatric center in Wallonia. One person from Zorgnet Vlaanderen, an important social profit employer's organization, was involved. The other interviewees belonged to non-specialized services (GPs, Kind & Gezin, youth care (AJ)) or adjacent sectors (AWIPH, CLB/PMS). From the 15 interviews, 6 had been interviewed earlier on the research trajectory, and 12 people in all had participated in either the roundtable discussions or the validation workshops. So, only 3 interviewees had no prior exposure at all to the process.

An overview of people involved in both interview rounds is provided in Table 3.

Table 3: Overview of people interviewed

Stakeholders	Exploration round		Consultation round	
	NL	FR	NL	FR
Child psychiatrists	3	3	4	**5**
Psychologists	1	1		**1**
General practitioners			2	
Paediatricians				
Ambulatory: CGG/SSM/AIGS	(1)			
Juvenile Justice				
Education			1	**1**
Youth Care				**1**
Patient/Child/Family rights		1		
Network coordination				
Prevention			1	
Administration (federal)	1			
Administration (Community/regional)		(1)	(1)	
Disability care				**1**
Social profit employers organisation			1	
Scientific institutions	(3)	(1)	(5)	**(3)**
Total	5	5	9	**9**
Target	**5**	**5**	**5**	**5**

2.2.3. Data analysis

The **semi-structured exploration round interviews** explored interlocutors' views on the current problems and bottlenecks in the CAMHS system and elements of a future, more integrated and effective system. All conversations were face-to-face, recorded and fully transcribed (around 120 pages of transcripts). One stakeholder contributed his input in a written document. The interview round started in July and finished early September 2011 (before the roundtables were held).

In order to structure the output of the exploration round interviews we rely on **a pragmatic framework** called a 'systems ladder', proposed by Donella Meadows as a way to think about different 'places to intervene in a system'.[41] The framework proposes a hierarchy of 12 so-called 'leverage points', inspired by the concepts and language of the discipline of system dynamics. Leverage points are elements of a system that decisively influence the way the system works. Blockages or malfunctions at the level of certain points will impede the system's functioning. Conversely, interventions at leverage points will have a significant impact on the system's behavior. The systemic nature of the framework lies in its proposed hierarchy of levels that have more or less structural impact on the system. For example, changing the goal of a system will have a profound influence on its functioning, whilst merely 'fiddling with the numbers' is, from a systemic point of view, a more anecdotal intervention. However, this does not imply that less systemic levers are not worth bothering with. They can be instrumental in changing the system's behavior. Furthermore, the higher one gets on the ladder the more risky and time consuming it tends to be to introduce changes in the system. So as a rule there is an argument to be made to think in terms of a portfolio of "interventions" across the whole Meadows ladder.

The categories proposed by Meadows can be used also as a framework to structure information from a diagnostic point of view, i.e. to map out what is wrong with a system. The 12 'places to intervene in a system' are usually presented in an inversely numbered way (ordered from the less systemic to the more systemic):

12 - Numbers: constants and parameters such as subsidies or taxes, such as the price of petrol in the example above.

11 - Buffers: the sizes of stabilizing stocks relative to their flows. These are aggregates of various types (people, finances, materials) that determine the system's behavior. Buffers that are small relative to their flows may lead to system instability. Large buffers may compromise the adaptiveness of a system.

10 - Stock-and-flow structures: physical systems and their nodes of intersection. This concerns the capacity of infrastructural elements that sustain a flux or flow in a system.

9 - Delays: the lengths of time relative to the rates of system changes. Delays in feedback processes can significantly determine the behavior of a system, often leading to instability (oscillations) if they are out of sync with the speed with which the system changes.

8 - Balancing feedback loops: the strength of dampening feedback loops relative to the impacts they try to correct. These are dynamic forces that keep the system near equilibrium, in much the same way as a thermostat keeps a room's temperature near a desired temperature;

7 - Reinforcing feedback loops: the strength of reinforcing, driving loops. These are dynamic forces that move the system away from an equilbrium (leading typically to phenomena of exponential growth);

6 - Information flows: the structure of who does and does not have access to information. Information flows are fairly obvious and easy to understand (whilst not necessarily easy to remedy) determinants of a system's performance and behavior;

5 - Rules: incentives, punishments, constraints, typically embodied by regulations of all sorts;

4 - Self-organization: the power to add, change or evolve system structure. This essentially concerns system features that allow it to learn and to adjust its structure and functioning to outside disturbances;

3 - Goals: the purpose or function of the system. This refers to the explicit or implicit goal(s) espoused by the actors working in and governing the system;

2 - Paradigms: the mindset out of which the system arises (its goals, structure, rules, delays, parameters). This refers to the basic norms and values which give meaning to the system's goals and functioning.

1 - Transcending paradigms, which is the ability to move flexibly between paradigms. We have chosen not to include this level in the analysis as it goes beyond the scope of this study.

The framework is used for diagnostic purposes. This means that all of these levels are ways of categorizing friction points in the Belgian CAMHS system, as indicated by the stakeholders and stakeholders interviewed. The framework is used in a pragmatic way to structure the rich interview output. In some cases diagnostic elements can be associated with different levels (leverage points), depending on how they are conceptualized. There is not one unequivocal way to conduct this analysis. Rather, the intent is to bring some measure of order to the interview output and stakeholder perceptions as a basis for a next step in the analysis.

Also **the consultation round interviews** were face-to-face, with one exception which was done over telephone. A very open list of questions was used to guide the conversations (Appendix 3). All face-to-face conversations were recorded. Given the relatively large number of interviewees and the short time available (6 weeks between mid-November and early-January 2012) no full transcripts were made but bulleted interview summaries. A few stakeholders who participated in the validation workshop (2 FR and 2 NL), and 1 FR expert child psychiatrist submitted more or less extensive written contributions.

Also the **3 workshops** were tape-recorded. These recordings were, together with field notes transcribed as bulleted interview summaries.

2.3. Evidence review

The study relies on an evidence base of topical research and relevant practices related to the Belgian mental health care system, particularly as it concerns children and adolescents. The compressed timeline of the project (7 months elapsed time) made a comprehensive and in-depth literature review impracticable. Furthermore, in Part I of this study a lot of the terrain had already been mapped out. Hence it was decided to focus on three key sources of information: a limited list of 'key documents', a set of studies and reports pointed out or handed over to us by stakeholders, and literature from various branches of systems thinking and innovation to support the methodology employed in this study.

Key documents included are:

- The first part of the present KCE project[9] including: a narrative review of organizational aspects of CAMHS; an international comparison study on the available evidence and knowledge about reforms and integrated care models in other countries (UK, Canada, Netherlands, France) and a mapping of the CAMHS landscape in Belgium.
- Other KCE-reports related to CAMHS: the evaluation of 'therapeutic projects' in mental health care[11]; psychiatric emergency care for children and adolescents.[10]
- A recent report prepared by the National Council of Hospital Facilities (Nationale Raad voor Ziekenhuisvoorzieningen, NRZV; Conseil National des Etablissements Hospitaliers, CNEH) for the Minister of Social Affairs and Public Health, containing an expert-based analysis of the actual problems and suggestions for future needs in the CAMHS sector in Belgium.[13]

2.4. Limitations of the methodology used

As described in section 2.1.1 and 2.1.2, the aim of the current study is to lay down the contours of the future CAMHS system. The "system" considered is not an organizational entity with recognized boundaries, legal status, resources, power and so on but it is an idealized system. This implies that, starting from the model and the recommendations that will be developed in this study, much of the organizational issues, implications in the legal domain etc. will remain to be worked out.

3. DIAGNOSTIC OF THE BELGIAN CAMHS SYSTEM

The first step in the conceptual modeling is the development of a root definition of the envisaged CAMHS system (section 2.1.2). This root definition succinctly captures the purpose (the 'raison d'être') of the system. The exact content of the root definition takes its cue from insights into the needs and concerns of children and adolescents with mental health challenges and other stakeholders (including parents, other family members, educators, medical professionals, other mental health professionals, and service providers across sectors). Additionally it is informed by an appreciation of the difficulties and dysfunctionalities in the existing care system.

Hence, there is a need for a diagnostic effort, mapping the problems and issues with the current system, to provide a basis for the development of an appropriate root definition. Typically, in a Soft Systems Methodology-informed approach, this diagnostic is captured by means of a 'rich picture' (section 3.3), or a visual representation of the system and its bottlenecks. In this participatory project the diagnostic is based on input from key stakeholders via interviews (section 3.1) and roundtable discussions (section 3.2).

To complete the picture of the existing system and its challenges, key documents and other literature sources were reviewed (section 3.4)

Disclaimer. It needs to be emphasized that sections 3.1-3.3 are based on statements of stakeholders. The quotation marks, and the synthetic headings and text fragments reflect stakeholder perceptions, not verified facts.

3.1. Diagnostic output from the roundtables

Two roundtable discussions were held - one for French-speaking and one for Dutch-speaking participants (Table 1). Participant totaled 17 for the French-speaking round table and 13 for the Dutch-speaking session (cf. Table 2).

The roundtables were organized around three key questions, of which only the first is diagnostically oriented: **"What image or metaphor captures, from your point of view, the essence of the existing CAMHS system in Belgium?"** This question focused on eliciting participants' views on the strengths and weaknesses of the present system. An inventory of all participants' responses can be found in the full report in Appendix 4.

The images evoked by the participants to the **Francophone roundtable** reveal the following strengths and weaknesses of the CAMHS system:

Strengths:

- Complexity, diversity;
- Pockets of goodwill, creativity, and efficiency.

Weaknesses:

- Lack of accountability, control, instability;
- Rivalry, lack of collegiality, coordination;
- Congestion and saturation leading to frustration, confusion, isolation and loss of meaning;
- Lack of political vision, short-termism, leading to stagnation;
- Lack of transparency hence difficult to navigate for users and professionals, no feedback;
- Lack of resources;
- Inability to adapt, dwindling degrees of freedom;
- Inability to cure, to fulfill its most basic purpose;
- Inability to resolve the tensions of a stressful, contemporary society;
- Source of stigmatization.

The images summoned by the participants to the **Dutch-speaking** roundtable point to the following strengths and weaknesses of the CAMHS system:

Strengths:

- Diversity, goodwill, expertise;
- Potential for learning, potential for establishing new connections;
- Pockets of efficiency;
- A discernible desire for reform.

Weaknesses:

- Overall ineffectiveness of the system;
- Unattractive, inhospitable and intimidating character; subject to taboos and stigmatization;
- Difficult to access, to navigate, to get out of the system, lack of transparency for outsiders;
- Complexity, fragmentation, chaos;
- Lack of an overall vision, of appropriate controls to steer and assess the quality delivered by the system;
- Subject to rivalries and lack of co-operation.

It is clear that the two groups of stakeholders overlapped considerably in their view of the mental health care system in which they are working (or with which they are interfacing). Its most conspicuous characteristic is **fragmentation and compartmentalization**. As a result young persons with mental health conditions and their families are disoriented and frustrated and do not receive optimal care and support. Also, as a result of the fragmentation **resources are used sub-optimally**, and the **effectiveness and efficiency of the system is compromised**. The fragmentation emerges from a long history of gradually increasing complexity, exacerbated by the lack of a clear focal point of management for the CAMHS system, lack of accountability, and competition and rivalry between actors in the system.

The participants in the roundtables also pointed to the **difficulty in accessing the system**, which is considered remote and inhospitable. Young persons and their families that are associated with the system are easily **stigmatized**.

There are **isolated pockets of good, state-of-the-art practice and efficacy** in the system, but the mental health care system has not capitalized on these as opportunities for learning and for building on these innovations towards widespread implementation of effective practices.

Both groups stressed the **presence of commitment, goodwill, and the potential for learning**. In addition, they noted that system participants recognize the entrenched systemic problems and are interested and **willing to consider significant reforms**.

3.2. Diagnostic output from the exploration round interviews

An exploratory round of interviews with 5 FR and 5 NL stakeholders was held early on in the study (July-September 2011; table 1). They were intended to explore interlocutors' views on the current weaknesses and strengths of the CAMHS system and their ideas for a future, more effective system. In addition, they focused on understanding the disposition of power in the present system and how that affects what is 'culturally feasible' in a change process towards an improved system. Finally, the interviews offered an opportunity for these key people to develop confidence in the participatory process.

To structure the rich output of the interviews, the diagnostic framework of 'Meadows Ladder' was used.[41] Interview quotes have been translated, shortened and are sometimes paraphrased. Each quote is labeled by a number that refers to the full quote, in the original language, in Appendix 5. As indicated above, it needs to be emphasized that all statements within quotation marks and the synthetic headings and text that precede them reflect stakeholder perceptions, not verified facts.

3.2.1. Numbers

The key number that stakeholders in interviews refer to is the fraction of the mental health care budget that is allocated to children and adolescents. There is a significant discrepancy between the prevalence of mental health problems in this age bracket (estimated at 20% by various stakeholders[k]) and the share of the total mental health budget it is entitled to. It was estimated that less than 5% of the total mental health budget is allocated to CAMHS.

Compared to the adult sector, the CAMHS is significantly underfunded

- **[1]** "I once calculated that only three percent of the total federal budget for mental health care was allocated to youth. While we are dealing with 20 to 25% of the total population."

3.2.2. Buffers

A key buffer that is mentioned is the shortage of practicing (child) psychiatrists. The profession is deemed unattractive for financial reasons and because the work is hard and stressful. Many psychiatrists choose to work in private practice, focusing on less complicated cases ('cherry picking'). Conversely, there is an oversupply of clinical psychologists. However, they are not recognized as 'health workers' and hence not reimbursed by social security. The supply of other, perhaps less traditional types of CAMHS providers has not been well developed.

Mental illness continues to be stigmatised in our society. This has implications for the attractiveness of the profession to young professionals.

- **[3]** "Twenty years ago, we used to have much more candidates for a specialisation in child psychiatry. Today there are not enough candidates to fill the training positions. I really think there is still a taboo around mental illness in our society. It is not seen as a genuine illness. People do not have the same respect for it as for a cardio-vascular disease."

Child psychiatrists choose not to work in hospitals but to establish their own practice that focuses on not too difficult cases as it is easier and more lucrative.

- **[4]** "Trained child psychiatrists don't want to work in a hospital anymore. The fees are such that it is much more attractive to have an independent practice to work with children that do not have too complex problems."

The profession needs to be made more attractive by creating opportunities for learning

- **[7]** "This reminds me of the issue of the continued training and support of professionals, with an eye to preventing burn-out and maintaining motivation. Because professionals are often confronted with very difficult situations that affect them at a personal level and require them to rethink their approach. And they have to be very creative too."

The official reimbursement of clinical psychologists remains a controversial point.

- **[8]** "Specific for the sector is the lack of child psychiatrists and the oversupply of clinical psychologists. The new nomenclature transfers final responsibility and financing to child psychiatrists only, with psychologists in a supporting role and being paid via the psychiatrists. This is a very hierarchic way of working that is not in accordance with the way it should actually work."

There is first line expertise that is insufficiently exploited.

- **[12]** "I have a strong impression that there are skills and experience that are not well taken advantage off. Educators on the streets who work on a daily basis with the most vulnerable children have something to say and they are only rarely listened to."

[k] This figure is widely cited and is based on WHO (World Health Organization) estimates (WHO. Atlas: child and adolescent mental health resources: global concerns, implications for the future. Geneva: WHO; 2005).

3.2.3. Stock-and-flow structures

There are long **waiting lists** for children and adolescents, both in outpatient (Centra voor geestelijke gezondheidszorg/ Services de santé mentale CGG/SSM) and residential services. The saturation of the mental health care system for children and adolescents is for many interlocutors an obvious and major shortcoming. Stakeholders pointed it out as **the key factor that compromises the effectiveness of the system** and that contributes to its negative image. Overall, traditional outpatient (ambulatory), inpatient, and residential services are the center of gravity of the CAMHS system. Flexible home-based and community-based mental health services and supports that are able to provide alternatives to treatment in inpatient and residential settings have not been widely put in place. Also the lack of emergency and crisis facilities is acute. These capacity problems bounce off one another and reinforce each other (see further: reinforcing loops), compounding the bottlenecks and aggravating the mental health difficulties and challenges for children and families.

The mental health care system for children and adolescents is unable to cope with demand. There are long waiting lists everywhere in the system.

- **[13]** "I believe that the waiting lists have been the biggest problem over the last few years. Certainly in the residential facilities and in daycare centres there are few opportunities for children (slightly more for adolescents) to be admitted in a crisis situation. So demand increases but neither youth care nor mental health facilities have developed an appropriate response. We are not structurally organised for these crisis admissions. I think this has been the most striking observation during my whole career, which goes back for almost 30 years."

Crisis and emergency services are saturated

- **[15]** "This is obvious from the demand for crisis and emergency facilities. The private practitioners feel more and more unable to cope and so they send people onward to the emergency facilities of general hospitals that are very quickly saturated. It's true that here in Brussels we do not have any facility for children and adolescents that caters for emergency cases."

Ambulatory services are underpowered

- **[16]** What strikes me as the most acute need in the mental health care system for children and adolescents is the absolute shortage of outpatient services. That's quite obvious from the long waiting lists we are coping with. In the French-speaking part the shortage is equally pressing. And there the terrain is even more fragmented with all these small day care centres."

3.2.4. Delays

The delays in the CAMHS system are a result of saturation of the care system, with ubiquitous waiting lists as a result (see: stock-and-flow structures, balancing feedback loops, reinforcing feedback loops).

3.2.5. Balancing feedback loops

The mental health care system is seen as a system under pressure. From the discussion under 'stock and flow structures' it is clear that there are a lot of capacity problems and bottlenecks in the system (see further also: reinforcing loops; information flows; power to self-organize). One reaction to these pressures is '**passing the buck'**, whereby saturated services pass on youngsters to other, more or less adequate, services (see: reinforcing loops). Another reaction is to implement localized initiatives to take pressure off of the system. Whilst these do help in meeting certain needs and offer opportunities for service innovation, stakeholders point out that typically these new capacities also are quickly saturated. The proliferation of **these isolated initiatives,** however well intended and executed**, contributes to the fragmentation of services** and of available financial resources. Furthermore, based on the experience of these new services quickly reaching capacity, actors in the sector are reluctant to undertake further initiatives. Thus, there are balancing loops operating at two levels. At a sectoral level, these isolated initiatives reduce the pressure on the overall system somewhat. They act as safety valves to keep the pressure on the system in check. However, whilst this is a laudable contribution, they represent a temporary 'fix' and many contribute to the system's inertia and resistance to reform.

Other balancing loops result from **bureaucratization** and control mechanisms that command too many of already scarce resources. Furthermore, also the **absence of a strong voice of an empowered**

family network can be considered as a balancing loop that reinforces the system's inertia.

Isolated initiatives take pressure of the system but are quickly saturated

- **[19]** "If I would take on more emergencies our department would run at full capacity all the time. But as so often, once the extra capacity is there, in two months time it is saturated. Taking the responsibility entails the risk is that one attracts all the misery of the French-speaking community."
- **[20]** "So I think the key problem is that the system becomes increasingly complex through the presence of these micro-networks that sometimes are working at cross purposes of one another, thereby compromising the quality of the intervention."

Fragmentation leads to facilities being stretched thinly and being under resourced

- **[21]** "So in Belgium there are many laudable initiatives. But at a certain point all these compromises lead to a budget that is being very thinly stretched. One grants resources here and there but with a risk of fragmentation and throwing in disarray the provision of care."

Bureaucratization compromises quality of care and requires too much resources

- **[22]** "The obligation to coordinate is fine but hopefully this does not imply more paperwork as we are already spending 25% of our time on that. That's the problem. Always these reports, reports, reports. So this whole issue of evaluation needs to be well thought through."

There is a perception that citizens themselves are only reluctantly empowered.

- **[23]** "What I am often confronted with, also in outreaching interventions, is how 'bed-oriented' people in Flanders are. That also applies to public opinion at large. People want you to take over from them. If you tell them that you'll come to their home, they don't want any of it. There's a cultural factor at play. And we also have a social system that is very pampering."

There is no patient organisation that works for and with parents of children with mental health problems[l]. There is no support (training) for advocacy and support organizations either.

- **[24]** "There is no patient organisation for children and adolescents. We tried, about ten years ago, but parents didn't want to be reminded of that. They don't want to share their experiences openly with others."

3.2.6. Reinforcing feedback loops

The CAMHS system is in many respects a system that is governed by reinforcing loops, steadily pushing the system away from a desirable, stable level of performance.

Capacity problems and bottlenecks in CAMHS have been signalled under 'stock-and-flow structures'. These **capacity problems reinforce one another**. Stakeholders acknowledge that there is indeed a dynamic of 'passing the buck' from one service to another: the lack of ambulatory capacity puts more stress on crisis facilities, which are quickly saturated and send children onwards to residential facilities where they don't belong. This leads to inappropriate and inefficient use of the available capacity of expensive, residential facilities. In addition, the system's ineffective response results in poor clinical and functional outcomes for both young persons and their families. These issues do not only manifest themselves within the sector of CAMHS but also in adjacent sectors such as youth care and juvenile justice.

Another important, exogenous reinforcing loop is an ever **increasing demand from young people and their families for mental health services**. This demand results from many coalescing forces operating at the level of broader society. These societal processes have not been fully elucidated in these interviews. However, stakeholders noted that the presence of mental health problems appears to be increasing and presenting problems are increasingly serious and complex.

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l There are a limited number of support groups for parents of children with very specific behavioral and mental health challenges, e.g. asbl Pétales - vzw Watnu (for parents of children with reactive attachment disorder), asbl TDA/H - vzw Centrum Zitstil (for parents of children with ADHD), vzw VVA Vlaamse Vereniging Autisme.

A demand-driving factor that has been mentioned and has the character of a reinforcing loop is the so-called '**target group' approach** to providing mental health services, whereby services are targeted to particular diagnostic groups or to particular types of problems, such as youth who have committed offenses. This is a clinical approach which distinguishes a progressively finer catalogue of mental and behavioural problems. However, categorizing and labelling these mental health challenges creates and reinforces its own demand both from users and providers (the latter wanting to sustain their raison d'être). This approach tends to limit services to particular priority groups and constrains the availability of help to the entire group of young persons needing mental health care and their families. Furthermore, the institutional response leads to greater fragmentation in the service landscape (another reinforcing loop; see: self-organization).

Lack of attention to cultural and linguistic differences among the communities in Belgium also leads to variable service delivery across the country and inappropriate services for each group. **Disparities in access to and in the quality of care** are experienced as a continuing problem for the CAMHS system, both in terms of the three communities and in terms of geographic disparities.

By their very existence, **waiting lists spur demand**. People, being aware of the bottlenecks, often register at several entry points at once hoping to get quicker access. However, this quickly inflates waiting lists beyond realistic proportions. Some stakeholders think that a centralised registration system for children entering the care system might create much needed transparency and more organized pathways to care (see: information flows). Care needs to be taken that information management tools do not lead to stigmatization as an unintended consequence.

Capacity problems reinforce one another. There is a tendency to pass on the buck.

- **[27]** "Brussels transfers the problems related to emergency cases to Wallonia because they are too awkward in terms of schedule. In Bertrix and Tournai people get complaints of patients, the criminal courts in Brussels and of Brabant Wallon because they have to travel too far to receive car or to pronounce their sentences."

The lack of co-ordination between first line and deeper end services leads to escalation in children's troubles and disturbances.

- **[29]** "The big frustration of GPs and other care providers is that when they send a youngster to a crisis facility, they get the message 'there is no indication, he doesn't fit in our group, etc. So they get them back and then later they are reluctant to send them onwards. As a result problems escalate to manifest crises and then you need the heavy residential facilities."

The number of young people that rely on the mental health care system for support keeps on growing.

- **[31]** "It's a fact that over the last couple of years there has been an increase in resources but unfortunately also an increase in kids and families in suffering. That is an observation that applies across sectors: health care, youth care and juvenile justice. All these lines are saturated by the number of children faced with difficulties in their families."

The existence of waiting lists leads people to demand-inflating strategies to access the system.

- **[34]** "The waiting lists are relative. The debate is too linear, as if the numbers represent reality whilst everyone knows that people put their kids on the list in four institutions to play it safely. The absence of a central registration point implies that it is difficult to put in a place an effective policy to deal with that situation."

A clinically informed target group policy creates its own demand.

- **[35]** "We have done research that showed that adolescents that ended up in addiction care became ever more addicted. It has to do with the care system where one is well received, where one feels at home, where people are nice for you and try to understand you. But you are only welcome as long as you are addicted. It's similar with these separate care circuits for kids with delinquent behaviour, autism or ADHD. For all other kids there is no dedicated support. So if you want to get help, you have to behave like a criminal, or an autist or a person with ADHD. The result is that the number of ADHD and autism diagnoses are rapidly increasing".

There is a reinforcing, demand-driven dynamic of ever increasing specialisation and fragmentation of the care infrastructure directed towards children.

- **[36]** "A target group policy leads to ever more target groups being identified. It's logical as youth care workers and medical professionals want to develop themselves further too. This clinical, hospital-based paradigm leads to an enormous fragmentation of facilities and there's no end to it. That is an immutable law of the clinical paradigm."

Sometimes assessments are tweaked in order to squeeze youngsters in a category where there is spare capacity (e.g. delinquent behaviour as a pretext for putting people in FOR-K beds).

- **[37]** "One of the perverse effects of this lack of coordination at the level of prevention and first line care is that one gets much more quickly to area of forced admission and hence the judiciary. For example, there is a child, 14 years old, that has been living in precarious conditions for years. We may think she prostitutes herself. We may think he has smoked a joint. Or a stolen mobile phone is found on him. Finally these delinquent behaviours are being used to give the youngster access to restrained facilities. One is going to call on the judge to place him in this or that institution in order to protect him somewhat. In fact, this is unacceptable."

Lack of attention to cultural and linguistic differences among the communities in Belgium also leads to variable service delivery across the country and inappropriate services for each group.

- **[38]** "We are probably the only bi-lingual hospital in Brussels. French-speaking hospitals are having a hard time with Dutch-speaking patients. I really dream of small facilities ('cells'), dispersed in the city and where people are always taken care of, adequate resources are present and both languages are spoken."

3.2.7. Information flows

The fragmentation of the CAMHS system is reflected in **a lack of structured and co-ordinated information flows between the actors in the system**, and between the sector and adjacent areas of youth services. The compartmentalization also affects informal networks within and across sectors. An important missing element is a reliable assessment of what the regionally-based demand for children and adolescent mental health services is.

There is a dearth of possibilities to establish informal, personal networks amongst health professionals.

- **[39]** "There has been a conference on forensic psychiatry organised by French-speaking professionals. The minister was there but also many juvenile judges and magistrates. In these kinds of settings it is easy to see how much we agree with one another. Then, when you call a juvenile judge, you are having a very different conversation. It's not an unknown person that suddenly forces you to do something. And that applies to both sides."

Lack of a centralised registration system.

- **[44]** "If you want to respect the rights of children, you have to make sure that facilities can continue to pursue an 'open door' policy, that systems are not saturated by insistent searchers that are always trying to find a new access point. In Holland you can have a ticket for an ADHD-investigation. But if that has been done you can't reapply for a period of three years."

3.2.8. Rules

This level connects directly to the following one, 'self organization'. Stakeholders point out that **hospital-centric CAMHS system** is governed by an elaborate regulatory framework that governs financing, the exercising of the medical and other mental health professions across disciplines, the management of a vast and costly infrastructure to support these services, and the rights and duties of patients and mental health and legal professionals respectively. This elaborate system of rules is not centrally administrated but rather is fragmented across different institutional levels (federal, regional and local) and sectors (mental health, youth care, education, juvenile justice). This leads to complexity,

compartmentalization, and a desire of influential actors to maintain to the status quo. In particular, stakeholders singled out the basic datum that the majority of financial resources are allocated to beds (i.e. residential facilities managed by psychiatric hospitals). Maintaining the 'bed' as the pivotal element of a mental health care system significantly constrains the system's ability to evolve towards a more integrated and effective approach to service delivery.

Another element that stakeholders often noted is the fact that policy making is hampered by the **absence of a transparent evaluation framework**. There is no assessment of the overall effectiveness of the CAMHS system. Evaluation methods are either non-existent or inappropriate, adding to the administrative burden of practitioners and constraining the ability for data-informed decision making and continuous quality improvement (CQI) at both the system and service delivery levels. Particularly the RPM/MPG (Résumé psychiatrique minimale/ Minimale psychiatrische gegevens) are singled out as missing the mark.

Financing in terms of beds does not allow for a fundamental reform of CAMHS.

- **[46]** "A bed is sometimes needed, not so much in terms of intensity, but because a child cannot be handled in its own environment. For crisis interventions it is just a matter of days. Sometimes it can be months. But, please, embed that residential treatment in an outpatient, child-and-family focused treatment. Not: 'I am going to put you in a bed, make you better and send you home. We're not talking about pre-care and post-care. I am talking about care, for which you happen to need a bed once in a while. That means that one has to be able to accept – and in the French-speaking part this will be easier than in Flanders – that not all partners are involved."

Hospital-linked resources cannot be flexibly allocated because of strict norms and regulation.

- **[47]** "Nowadays hospitals keep thinking in terms of units, the staffing ratios and the money that is associated with that. They hesitate to allocate that budget outside of the hospital, also out of fear of being reprimanded by inspection authorities."

Interfacing with juvenile justice is difficult because of the strict judicial framework.

- **[49]** "Magistrates have to reduce something very complex into a binary datum. For example, if a young person says that he does not feel like receiving care, a magistrate has to put in his injunction whether the patient agrees or not. It's yes or no. We would say that he is ambivalent, that he is asking himself questions. He thinks about advantages and disadvantages. We consider him as a process. We will say to the magistrate: 'please listen to him before or after the appeal period to consider whether or not he has to stay with us.' So we need to rethink the clinical practice to enable them to translate it into judicial language."

Fragmentation is also embedded in legal frameworks and in responsibilities allotted to different institutional levels.

- **[52]** "When you have all these levels of power – federal and federated – how do you expect people to find one another? We will never return to a single ministry of public health as we had in the old days. Hence, it is necessary to clarify the role of each at the different levels and their administrations. Each has to acknowledge the competences of the others (not anymore: 'it's not my job, up to you to take charge') so as to avoid gaps in dealing with abandoned and violent youngsters and with emergency cases."

Fragmentation is also used opportunistically by the actors in the field to advance their own agenda.

- **[53]** "It is a fact that people feel quickly threatened when integrated models are on the horizon. Everybody pays lip service on the condition that they can continue to call the shots. That's reinforced by the fact that this one can go and cry at the federal level, the other on at the Flemish level, yet another with the justice department, or public health."

There is a lack of appropriate evaluation methods.

- **[56]** "We have been doing the RPM (Minimum Psychiatric Data) for 10 years and it has absolutely no added value. It takes me a quarter of my time as a psychiatrist to fill that into the computer which crashes 75% of the time because their software is not very stable. We've been entering these data and nobody has been able to tell us at the 10th anniversary of the system, what was being done with them. Nobody has published anything which could help us to focus our work. Finally one wonders whether this whole thing only serves to protect the five jobs that have been created by it."

There is no assessment of the overall effectiveness of the existing CAMHS system.

- **[58]** "There is very little research on the effects of mental health services offered in Belgium. Children arrive at the cabinet of someone who calls himself a therapist. He or she does something with the child, or not. Does anything change? As far as we know the effectiveness of the system is zero. In the best of cases it's as effective as the placebo effect."

3.2.9. Capacity for self-organization

The capacity of a system to self-organize is its capacity to learn and to adjust its structure and operation in response to outside disturbances. One of the most conspicuous features of the Belgian mental health care system as pointed out by the interviewed stakeholders and by those participating in the roundtables is its level of **fragmentation and compartmentalization**. This makes it difficult for users and professionals to navigate the system, to exchange information (see: information flows) and to develop a shared vision of purpose and governance of the system (see: goals). The result is that the system generally lacks **the capability of adjusting to changing conditions[m].**

[m] Although there are examples of successful cross-sectoral collaborations having been set up, as for example in Wallonia where for juvenile delinquents with psychiatric troubles care infrastructures with concertation networks were established and financed

The CAMHS system's compartmentalization is to a significant extent determined by institutional factors (see: rules) and by legacy infrastructures and vested interests. The interviews also revealed that the very nature of the 'target group' paradigm (i.e., providing specialized services limited to particular diagnoses or target groups) that informs contemporary health care systems contributes to fragmentation (see: reinforcing loops). In response to outside pressures, **ad hoc initiatives are set up to meet certain acute needs**. However, whilst these initiatives often make a positive contribution, at the same time they make the care system even more difficult to navigate (see: balancing loops).

Furthermore, the fragmentation is to an extent also rooted in the training of medical and other mental health professionals. This training typically focuses on the child as an individual (without taking into consideration the family and the wider context) and on working within a particular functional module of the care system (without having a wider view of the system). **Professionals are not trained to cooperate within and across sectors** to ensure a collaborative approach to service delivery. Similarly, professionals in primary care or in adjacent sectors have limited skills and processes to detect mental health or behavioral problems and to seek specialized services when indicated.

The CAMHS system is very fragmented and compartmentalised, and hence difficult to navigate.

- **[60]** "The disadvantage with our federal policy is that it takes the hospital law as a starting point. That's like a tree to which constantly new branches are added. The result is a diversity that is difficult to manage globally."

Legacy infrastructures and vested interests dampen and limit the possibilities for institutional reform.

- **[63]** "Radically adopting a networks structure implies that you have to let go of financial resources. This is for many partners a bridge too far. Because they do not want to transfer all the privately accumulated resources to the government or the population. This is a major stumbling block when moving towards a regional coordination."

The growing differentiation in mental and behavioral problems leads to institutional fragmentation which is harder to govern and co-ordinate.

- **[64]** "At the end of the day you are sitting with sixteen professionals around one child. And you have constantly groups that are making a case that something has to happen around a certain facet of the problem. That's a problem of clustering. And the increasing regulation implies that people are keeping an eye on what they don't have to do. One organisation says: we are focusing on very small children. Others specialise in teenagers. There are centers for drugs, for traumapathology. The field is further parcelled out. But who is steering this centrally? Who is evaluating all these partial contributions?"

The medical professional needs to be trained to collaborate with other parties.

- **[65]** "I think that there is a real need to learn to work together as we have been much influenced by individual-oriented models. And that includes psychiatry, as the discipline starts from the patient who suffers from a psychiatric illness. However, in case of children and adolescents one has to forget that point from the start."

Professionals in adjacent areas need to be trained to pick up early signals related to mental health and behavioral problems.

- **[68]** "Also professionals in adjacent sectors need to be trained to pick up early signs of discomfort. There also the formation of networks is important to train these other professionals."

3.2.10. Goals

The goal of a mental health care system for children and adolescents entails three key dimensions. One has to do with **the scope of services** provided by the system: is it focused on the child only or is it focused on the child, family and relevant social environment? Several stakeholders in the interview sample were of the opinion that the existing system is too centered on the child in isolation without consideration of the family and the environmental context in which the child functions (i.e., school and community).

A second key dimension relates to a **developmental perspective**. The needs and challenges of young persons evolve as they move from early childhood to young adulthood. To what extent is a mental health care system willing and able to adapt interventions to different stages of the developmental spectrum (specifically to young children and their families and to youth in transition to adulthood)? Stakeholders saw too few services that take this temporal perspective into account.

A third key choice revolves around the distinction between a '**target group' approach** - catering for young people with an already identifiable disturbance or pathology - **versus a 'population approach'** that sees the improvement of the psychosocial skills of all children (those with and without mental health problems) as the goal of the CAMHS system. They pointed out the need for a balance between serving young persons with diagnosable disorders and a broader 'public health approach' that also includes strategies for mental health promotion, prevention of disorders, and early identification and intervention in addition to treatment for young persons with identified mental health conditions and their families.

From a policy standpoint, there is no clear, agreed-upon goal for the CAMHS system. Without being anchored in a clear understanding of its goals, the system is driven by the interests of institutions instead of the needs of young persons and their families. Given the lack of clearly defined goals, there is also a lack of clearly defined desired outcomes for the CAMHS system to be used to design the system and to deliver the services and supports needed for achievement of the specified outcomes.

The system is too child-centered and does not focus enough on its social environment, particularly the family.

- **[69]** "Take a classic example. A child has a cognitive disharmony. Doesn't feel well at school. There are learning difficulties. Small emotional problems develop into relational problems. Nowadays parents don't know how to handle a normal child, much less a child with complications. And there psychiatrists need to accept to work a little more '*orthopedagogically'* with a family. Because one loses a lot of time with very child-focused treatments whilst disregarding the psycho-educational context with the family."

There is very little in terms of initiatives or infrastructures that take into account a developmental perspective.

- **[72]** "In my experience care models need to take into account age brackets of about 6 years: 0-6 covers the question of development, 3-9 is the question of learning, 6-12 is childhood and hence the issue of the relationship to the parents, 9-15 is puberty and the management of sexuality, of the paternal function, the process of positioning with respect to the law, of respecting the collective, to live together. Then there is 12-18 years old. Most adolescent services focus on this age bracket (or on 14-18). I continue: 15-21 is the period of orientation, life choices, partner choice, etc. And 18-24 is the category of 'young adults old adolescents'. These age brackets have to be served by specific projects. But I see very few of these specific projects."

At this stage much of CAMHS (and youth care in general) is driven by a clinically-oriented target group approach. A population-oriented model investing in the general wellbeing of all children is more appropriate. A clinical approach can be grafted onto this population approach but should not be leading.

- **[73]** "In the population paradigm, approaches are deployed to support the whole population. For children this boils down to air, nutrition and education. We can't do very much about genetic predisposition, maybe for the better. We can do something about those contextual factors. Another thing is: make people stronger instead of more dependent. The clinical model makes people dependent. Don't pollute schools with the clinical model. If kids are difficult to handle at school, make teachers stronger to deal with that situation. Don't immediately think ADHD. If nothing works and it breaks down, than a clinical intervention maybe appropriate. Also I don't believe in the effectiveness of screening. It is too aspecific and the risk for false positives or false negatives is too large."

There is no overarching, inclusive model of the children and adolescent mental health and youth care sectors to guide policy.

- **[74]** "Why is child-abuse relegated to youth care but when it leads to unpleasant consequences it becomes child psychiatry? At government level there is no inclusive model. This is an essential paradox: how can you expect to come to an integrated model when the management does not happen from an integrated model?"

In absence of a shared, foundational goal, reform movements tend to be guided by the interests of the institutions rather than by children's needs.

- **[77]** "What I find a relevant question is how much we want to spend as a society on youth care and how effective this is. This includes education, physical disability care, youth wellbeing, family support etc. That is a very fragmented landscape. Integral Youth Care was an attempt to do something differently, but it has been a disappointment. Because the government has not put the children and adolescents in the focus but the interests of the institutions. Integral Youth Care does not start from the question what the child actually needs."

3.2.11. Paradigms

The shape of the CAMHS system is a reflection of fundamental views held by the medical profession (and by extension by the entire society), with respect to the nature of childhood, the nature of mental health conditions in children, and the kind of care that is appropriate for this distinctive group of children and families. There seems to be a consensus that **children cannot be considered as 'little adults'**. The concept of mental health for this group needs to be refined and made explicit and taken as the basis for a care system. On the other hand medical professionals have a hard time considering children and adolescents as stakeholders regarding their own troubles, and hence as partners and co-creators of their own care trajectory. The existing mental health care system is traversed by the idea of guilt (of parents, of society vis-à-vis children) and victimhood. It would be more appropriate to relinquish these notions in favour of a concept of responsabilization, in which a social collective takes charge of a process of resilience, healing, and improved functioning. Finally, the fundamental right of all children and families to effective services and supports and to drive their own care is seldom taken as a cornerstone of a health care system.

Children are not 'little adults'. They have specific developmental needs. The concept of children's mental health needs to be clarified and taken as a cornerstone for a care system.

- **[78]** "Children are not little adults. There is the dimension of development. The way a child perceives the world is very different. Acting as if children are adults is doing them a disservice."
- **[80]** "For children it's not only an issue of the mind, it involves the whole psycho-motor dimension, the work with the body. A child is a being in development. So it is not really possible 'to take care' of a child. It's not only a matter of struggling with his problem, but to allow him, whatever the issue, to develop whatever his/her brain needs at that point in time."

The worldview underpinning a mental health care system needs to evolve from polarizing victims and wrongdoers to responsabilizing a social collective in a process of healing and reintegration.

- **[83]** "Indispensable value for me: adolescence is a time of the social, so it is necessary to rehabilitate the social, the being-together and the value of responsibility, not of responsibilization. Responsibility because we are not looking for who's guilty. The status of victimhood puts a lot of people in a bind."

The rights of children should be a foundational element in determining the kind of care system that ought to be developed; children and their families ought to be in the driving seat, not the care infrastructure.

- **[85]** The Convention on the Rights of the Child has to play an important role. This says that each child needs to be offered a comparable level of care, whatever the circumstances. That is not the case in our care system. That is a consequence of this target group approach. Respect for the Convention means that children are not prematurely put into target group but that they are guaranteed that their development will be put in a broad perspective."
- **[87]** "On the whole young people live in a society that extols the value of individual achievement. Their personality is negated on a continuous basis. They are not given the possibility to express themselves, to participate. And that is a form of abuse at a time when a discourse of participation and citizenship is so conspicuous in society."

Children and adolescents are still too often considered as not capable of taking up responsibility in their own treatment. They need to be educated and supported to take up that role.

- **[88]** "People used to say: patients can't contribute. They don't have the background. Well, then you have to put something in place to make this possible. But there are signs that this is being taken up."

3.2.12. Summary of systemic problems

The analysis identifies the key points raised during the interviews. It demonstrates that the problems besetting the CAMHS system go beyond highly visible and conspicuous dysfunctionalities, such as waiting lists and lack of crisis capacity (acute they may be). Friction points have been flagged at all levels of the ladder, revealing the systemic nature of the challenges. The system can basically be seen as being under pressure of escalating forces (reinforcing feedback loops): demand has been on the increase for which the care system is not able to cater. Service capacity is saturated, and care providers react by passing on the buck. The system is fundamentally unstable. Services are constantly putting out fires rather than taking a pro-active approach to implementing a well-designed and rational system of services and supports (balancing loops). Isolated initiatives are undertaken to locally relieve pressure, but they are quickly saturated too. The focus on these local experiments (that are not integrated in the wider system) hamper structural reform. These ad hoc initiatives are a symptom of sectoral and institutional compartmentalization, which they help to reinforce.

Fragmentation is at the root of the system's inability to address the pressures it is confronting. Fragmentation results from powerful forces such as: legacy infrastructure, vested interests and legal frameworks. Information flows between different parts of the care system (and between the mental health care system and adjacent sectors) are inadequate, resources are scattered, and there is no overarching vision on care for people in this age group. At the level of 'paradigms,' it appears that the system is captive of a conception of youth and youth care that is challenged by stakeholders. Rather than considering children as young, helpless versions of adults, a perspective is advocated in which young

persons appear with specific developmental needs and who can, together with their families and social environments, be empowered as full partners in service delivery and as the drivers of their resilience and recovery.

The following table organizes the systemic problems related to the CAMHS system that were identified in this analysis. It is clear that problems exist both at the system level and at the level of delivery of direct services to children and their families. Both of these levels should be addressed to design a comprehensive approach to system reform that results in a more efficient, and effective CAMHS system that results in improved outcomes for young persons with mental health challenges and their families.

Table 4: Overview of issues affecting the existing Belgian CAMHS system arranged in accordance with 'Meadows Ladder'[41]

Leverage/Intervention Points	Systemic Problems
12- Numbers	• Lack of financial resources • Inappropriate allocation of resources to CAMHS relative to the investment in mental health services for adults
11 – Buffers	• Lack of a workforce (provider network) that is prepared to provide state-of-the-art services and supports
10 - Stock-and-flow Structures	• Lack of service capacity • Limited range of service • Lack of home and community-based services • Overreliance on inpatient services
9 – Delays	• Lack of capacity and saturation of services and resultant significant waiting lists for care
8 - Balancing feedback Loops	• Reliance on inappropriately services due to lack of service capacity • Pockets of excellence in service delivery approaches that are not adopted and implemented system wide • Isolated services created to reduce pressure on the CAMHS system that result in additional fragmentation • System inertia and resistance to system reform
7 - Reinforcing feedback loops	• Continued growth in children and families' demand for mental health services • Lack of coordination within and between sectors and both the system and service delivery levels exacerbate capacity problems and compromises clinical and functional outcomes for young persons and their families • Waiting lists lead to users' demand-inflating strategies to access the system • Reinforcing demand-driven dynamic of increasing specialization and fragmentation in care services for young peopl.

Leverage/Intervention Points	Systemic Problems
	• Lack of strategies to address cultural and linguistic differences and disparities in access to and the quality of services
6 - Information flows	• Fragmentation at the system and service delivery levels • Lack of structured and coordination flows of information
5 - Rules	• No clear focal point of responsibility, management, and accountability at all levels • Systemic focus on “beds” and hospital-based services rather than a full range of services and supports • Lack of data for data-based decision making and continuous quality improvement at both the system and service delivery levels
4 - Self-organization	• Fragmentation of services both within the mental health sector and across other child-serving sectors • Focus on the child in isolation rather than in the context of the family and the wider environmental context • Lack of training of mental health professionals on a family focused and “ecological” approach to service delivery
3 – Goals	• No clear, agreed-upon goals for the CAMHS system • Lack of clear, agreed-upon desired outcomes for the CAMHS system • Lack of an appropriate focus on young persons across the developmental spectrum • Lack of a balance between treatment for young persons with identified mental health conditions and a “public health approach that also includes mental health promotion, prevention, and early identification and intervention • Lack of specification of a value-based practice approach for the entire CAMHS system
2 Paradigms	• Lack of family and youth partnerships at the system and service delivery levels • Lack of family-driven, youth-guided care
1 - Transcending paradigms	• Not Applicable

3.3. Consolidating the diagnostic insights in a 'rich picture'

From the discussion above it is obvious that **many of the issues and friction points** raised by the interviewees **are interconnected**. In an attempt to make some of these interdependences explicit, an 'influence diagram' can be drawn. This is one possible format for a 'rich picture' that is intended to give a synthetic overall image of the system under study. The diagram shows how 'friction points' influence one another (as indicated by arrows). The wiring is based on stakeholders' perceptions as captured by the interviews. It is, therefore, not a picture of 'reality' but a reflection of the complexity embedded in stakeholders' opinions.

The arrows are intended to illuminate the systemic architecture behind the key dysfunctionalities of the system. Some sequences of friction points and arrows form closed loops, either reinforcing or balancing. Given the presence of many of these loops, there is not one correct way to read the diagram. A convenient approach is to begin with the **increased demands** for child and adolescent mental health services (left-hand side of the diagram, at halfway height). This is driven by a resultant of many exogenous, societal drivers.

The increased demand **puts pressure on** the sector's inpatient, outpatient and crisis/emergence **capacities**, leading to waiting lists. The presence of **waiting lists** and other **bottlenecks** leads to inefficient use of existing infrastructure. For example because of insufficiently child-specific care, haphazardly structured care trajectories and long residence lengths of stay for children in psychiatric hospitals occur, which in turn lead to **suboptimal experiences and outcomes** for both children and families.

Practitioners in the field experience these problems on a daily basis. The existing 'bed'-oriented infrastructure cannot flexibly accommodate these pressures (because of the financing streams that are associated with it). As a result, **localized initiatives** are implemented at the margins of the care system to resolve some of these problems (arrow from 'suboptimal patient experience' to 'ad hoc initiatives'). These initiatives do respond to genuine needs, but are not part of a broader strategic framework and hence contribute to sectoral fragmentation. This **fragmentation** is driven and maintained by a mix of factors: institutional fragmentation (between different governance levels and policy domains), ideological differences (between regions and confessional pillars), and by medical professionals' lack of collaborative perspectives and skills.

The sectoral fragmentation leads to **inertia and a lack of capability to reform**. The stasis is reinforced by **vested interests** (those who wish to maintain the status quo) and **bureaucratization** (particularly in a strictly regulated sector such as hospitals). The inertia reinforces the need for ad hoc initiatives, which leads to further fragmentation of the sectoral landscape and resources. **Scattered resources** contribute to inappropriate and ineffective use of the existing infrastructure. Sectoral fragmentation makes it not only difficult for policy makers and professionals to navigate the system, but also for children and their caretakers. This further contributes to their suboptimal experience.

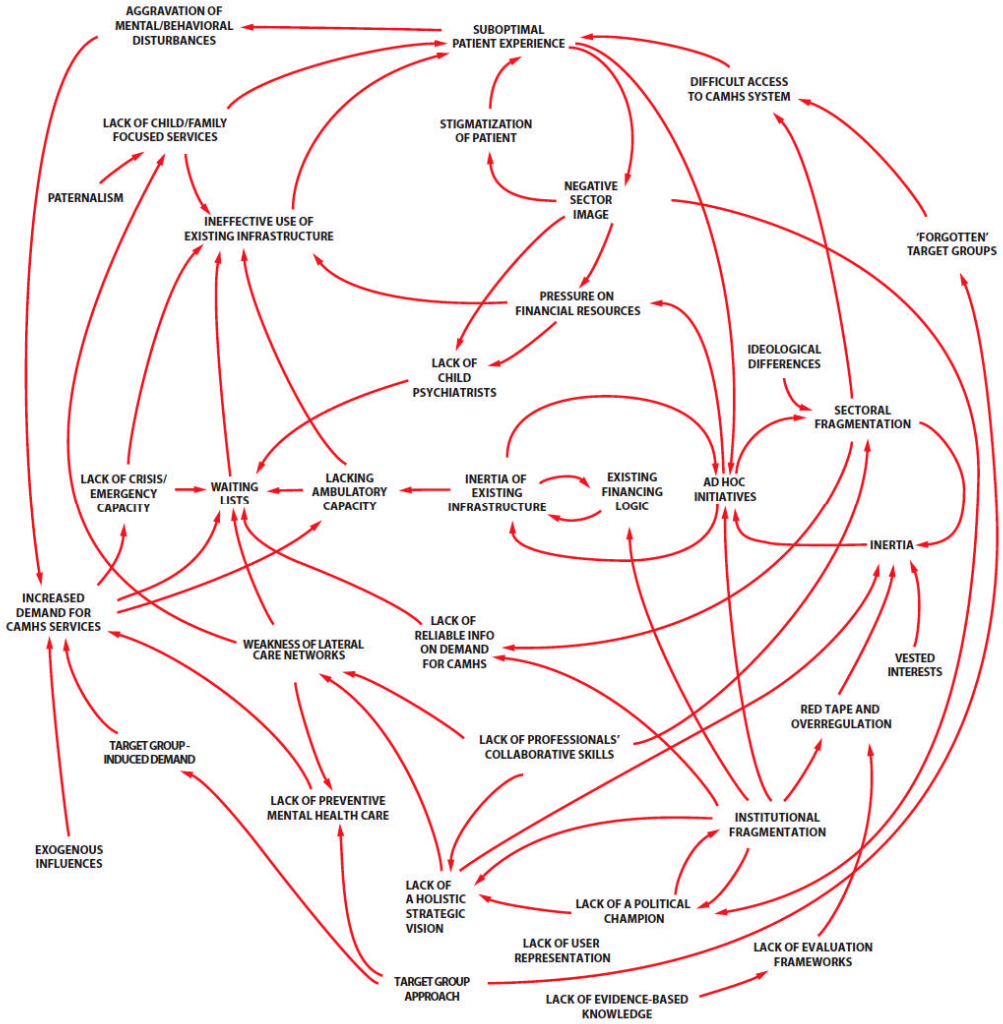
The sectoral and institutional fragmentation, the **negative mental health sector image** (still loaded with stigma and taboo) and the **absence of an active citizen platform** (there is no family organization specifically for parents of children and adolescents with mental health problems or a youth organization) make it hard to mobilize a **political champion** for reform of the CAMHS system. Fragmentation and lack of political support engender the **absence of** an holistic, strategic **vision** for the sector, which reinforces the inertia, and the weakness of lateral (cross-sectoral) care networks. The latter contributes to the **paucity of** individualized, coordinated, family-driven and youth-guided **services**.

Fragmentation is also tantamount to a **deficient inter/cross-sectoral flow of information**. One of the elements pointed out in the interviews is the **absence of** reliable information on the need for children and adolescent mental health services.

A final element in the diagram is the **target group approach** that currently undergirds the CAMHS system. It has some **unintended consequences**. There are always 'forgotten' target groups that have difficulties accessing the system. Identifying target groups and creating dedicated services creates more demand for these services. Furthermore, it comes at the cost of serving all young persons with mental health treatment needs as well as preventive interventions (population-based or public health approach).

The diagram is complex and difficult to decipher, but reflects the complexity and disorganization of the current CAMHS system and the many leverage points that can be targeted in system reform efforts.

Figure 2: 'Rich Picture' (influence diagram)



3.4. The diagnostic assessment of the National Council for Hospital Facilities

An ad hoc group to the permanent committee 'Psychiatry' of the National Council for Hospital Facilities has recently completed a set of recommendations for the reform of the CAMHS system in the context of the development of care networks as envisaged by Article 11 of the Hospital Law.[13] The recommendations are based on an assessment of the priority needs within the CAMHS system and in adjacent sectors (paediatrics, youth care, disability care, juvenile justice and substance abuse).

It is useful to contrast the key observations made by the working group with the diagnostic elements discussed earlier in this report. The points raised by the group need to be understood against the background of an understanding of what constitutes state-of-the-art, cost-effective mental healthcare for young people. The approach advocated relies on cross-sectoral integration, making sure that children and families as much as possible receive care in their natural environment and are actively implicated in shaping a strength-based, multi-systemic care trajectory.[13] The group's key diagnostic observations are:

- An increasingly diverse and complex society leads to growing demands for mental health services for children and adolescents;
- Whilst the CAMHS' capacity has progressively expanded over the last 15 years, the global care capacity in the children and adolescent mental health care sector is still markedly insufficient and lags behind the adult sector (currently only an estimated 60-70% of that required care capacity is realized - the benchmark figure is the 6% of youth population that typically requires clinical intervention for mental health problems). More than 20% of psychiatric admissions of youngster older than 15 happens in adult facilities. On top of that there are serious geographical imbalances in the care offering;
- A move to a family and community-based care model is hampered by a significant lack of outpatient service capacity, crisis and emergency facilities and in mobile 'assertive care' (the latter refers to flexible psychiatric care in the natural environment for youngsters with complicated difficulties);
- There are gaps in care trajectories due to a weak coordination between different care services and areas, leading to inappropriate access, 'shopping' and belated specialized diagnostic and treatment;
- There is lack of a skilled workforce. Incentives have to be put in place to attract more child psychiatrists. The contribution of clinical psychologists and 'masters in educational sciences' need to be officially recognized. Outreach work needs to be rewarded;
- Care givers and educators in adjacent sectors need to be supported in developing their mental health oriented skills. The psychological and psychosocial function in paediatrics needs to be reinforced. Currently this external liaison function is only haphazardly supported by the CAMHS sector;
- Prevention, detection and early intervention pay significant dividends, particularly in the case of young people. Promising initiatives in this area – particularly those that target the parent-child nexus - need to be consolidated and expanded.

It seems there is a significant overlap with the observations from the roundtables and interviews (see Appendix 4, 5 and 6). Compared to our own assessment, the National Council's advice puts a heavier emphasis on the lower-numbered leverage points in Meadow's[41] Systems Ladder: the lack of financial resources (Numbers), the lack of skilled workforce (Buffers), the lack of service capacity (particularly in outpatient and crisis/emergency services; Stock-and-Flow structures). Within-and cross-sectoral fragmentation is acknowledged and seen as an important hurdle to realizing a more cost-effective, coherent, strength-based, youth-guided, and family-driven service offer. The members of the ad hoc working group seem to be confident that there is a strong enough consensus between stakeholders (professionals, parents and children, administrators at different institutional levels) regarding the value base and guiding principles of a reformed CAMHS system to transcend the current fragmentation and limitations in service offering to move towards a more effective care system.

4. DEVELOPMENT OF A POLICY SCENARIO FOR THE ORGANISATION OF CAMHS IN BELGIUM

In this section the focus shifts from a diagnostic perspective to identifying solution elements that could potentially give direction to a reform towards a more effective CAMHS system. These elements will be extracted from the participatory process and from key research studies and policy documents. Subsequently, diagnostic and solution elements give input to a root definition, an activity model and a stakeholder mapping, respectively. These will form together the constituent elements of a future CAMHS scenario.

4.1. Solution elements

This study starts from an appreciation of the friction points in the existing CAMHS system. Hence, in the previous section the focus was on a diagnostic analysis of the existing system based on stakeholder input via interviews and roundtable discussions. The observations were contrasted with the analysis of the most urgent needs on which the recommendations of the National Council for Hospital Facilities are based.

In this section an inventory is made of the solution elements that have been proposed by stakeholders during the face-to-face interviews and roundtable discussions. Additionally, based on the insights of Part I of this study[9] and other related KCE-projects[10, 11], the 'System of Care' approach is discussed as a source of relevant solution elements for a future, more effective mental health care system for children and adolescents. Finally, also key solution elements from the National Council recommendations are highlighted.

4.1.1. Solution elements identified from the roundtable discussions

The two roundtable sessions (Flemish/Walloon) assembled a group of 30 stakeholders in total (17 French-speaking, 13 Dutch-speaking cf. Table 2)[n]. The discussions were organised around three questions, the first of which was diagnostically oriented (identifying the strengths and weaknesses of the present CAMHS system by means of synthetic images or metaphors: cf. section 3.1). Two further questions submitted to roundtable participants were solution-oriented:

- **What is the purpose (i.e. 'raison d'être') of a CAMHS system?** And how does this purpose reflect the specificity of the target group(s)? This question aimed to elicit responses that help to understand what the fundamental contribution of an idealized CAMHS system (independent of the constraints of the existing system) should be. The subsidiary question aims to understand to what extent focusing on children and adolescents shapes the system's purpose.
- **What are your top 3 interventions to improve the deficiencies of the existing system?** Here the question aims to map out directions for interventions to move from the present situation to a more effective CAMHS system.

In this report only the headlines of participants' responses are summarized (Full inventory responses: Appendix 6).

What is the purpose or "raison d'être" of a CAMHS-system?

In response to the question what the fundamental contribution of a CAMHS system is, there was a consensus (across language-based sessions) that the system ought to be oriented towards responding to the needs of young people with mental and behavioural problems so as to enable them to eventually take their place in adult society as well as possible.

[n] In the French-speaking group there were no representatives of patient organizations and youth care present. In the Dutch-speaking group representatives of education, juvenile justice and patient organizations were absent.

There are three key dimensions underpinning this 'raison d'être':

- A **temporal (developmental) perspective on needs**: children are people who are rapidly evolving along a developmental trajectory; different stages in that trajectory are associated with distinct patterns of needs; diagnostic capabilities, care and cure need to orient themselves towards these developmental specificities.
- A **broad ('ecological') conceptualization of needs**: diagnostic capabilities, care and cure are not only directed towards the suffering 'patient' but also to his/her social environment (family, friends, school environment and others). The notion of 'care' therefore extends beyond what can be considered as 'specialized' care.
- The **care system's ability to learn and to adapt**: at a meta-level there is need for system functionality that is oriented towards learning and self-repair in line with evolving societal circumstances (and hence with evolving expectations regarding children's functioning), with changing patients', families' and professionals' needs and with the presence of tensions in the troubled child and adolescent.

As regards the scope of the potential target group, participating stakeholders agreed that the CAMHS system ought to help all children in developing their psycho-social abilities, whilst the core finality of the CAMHS system (providing care) is focused on children with difficulties.

The role of the young person and family was not fully elucidated in this reflection as it did not confirm to what extent the child and his/her family ought to be driving the care provision process. In other words: is the child/family a recipient of personalized care or is it also a partner and co-creator in the healing process?

Whilst the CAMHS system goes beyond specialised care, this does not mean that anyone is able to contribute to the system. Provision of care in the broad sense remains in all cases linked to having the requisite expertise. The notion of 'evidence-based' practice, however, is controversial, and more so for the French-speaking stakeholders. There is a suspicion that this is shorthand for an essentially reductionist and simplistic reasoning that leads to unwarranted constraints on the therapeutic repertoire of the medical professional.

What are interventions to improve the existing system?

A third and final round of discussions at the roundtable sessions proposed a set of 10 possible interventions as a starting point for a reflection on how the existing system could be improved. These interventions were derived from the 'System of Care' framework[14] without participants being specifically informed about this origin. The interventions proposed were:

1. Developing comprehensive home-and community based services and supports;
2. Developing family partnerships and family support;
3. Providing culturally competent care and reducing unmet need and disparities in access to services;
4. Individualising (personalising) care;
5. Implementing evidence-based practices;
6. Coordinating services, responsibility and funding to reduce fragmentation;
7. Increasing prevention, early identification, and early intervention;
8. Strengthening early childhood intervention;
9. Expanding mental health services in schools and other adjacent sectors;
10. Strengthening accountability and quality improvement.

Participating stakeholders were then invited to propose their top 3 of interventions to improve the existing CAMHS system. They were invited to go beyond the proposed list of 10 if they wanted to. Across the two roundtables following observations were made:

- In identifying appropriate interventions for improving the system an ambition to realize a sectorally (between outpatient and residential services) and cross-sectorally (between mental health and adjacent services) more integrated care system dominated (intervention number 6).
- A second key intervention was to make the system more child and family-centered by providing customized (personalised) care, preferably in home and community settings, and by establishing family-partnerships (interventions numbers 1, 2 and 4).

- A third point of gravity was the strengthening of prevention, detection and early interventions (intervention numbers 7, 8, 9). However, stakeholders in both language groups were acutely aware of the potential unintended consequences (lock in, stigmatization) of early detection.

The most emphatic divergence between the two language-based sessions seemed to center around the notion of 'evidence-based' practices (intervention nr 5 and also 10). On the French-speaking side a lot of caveats were voiced in relation to the orthodox evidence-based discourse which is seen to be ideologically and commercially motivated and may lead to an unwarranted simplification of the therapeutic strategies at the disposal of the care provider. Also Dutch-speaking stakeholders voiced some additional qualifications when it comes to evidence-based ('not narrowly focused on the disturbances but connected to the aim') but did not seem to find this controversial and some of them advocated it strongly. In the remainder of the analysis reference is made to the 'evidence based' nature of care but understood as not to exclude therapeutic approaches that yield promising results but have not been thoroughly scientifically validated.

On the whole, suggested interventions did not go beyond the scope of the list of 'System of Care' derived principles. The key points reiterated above span the whole spectrum of that list. Only the third item ('providing culturally competent care and reducing unmet need and disparities in access to services') was not picked up at all in any of the proposals.

4.1.2. Solution elements from the exploration round interviews

The 10 interviews with stakeholders (see table 1) not only yielded rich insights into the current problems and bottlenecks in the CAMHS system but also allowed to explore interlocutors' views on what potential solution elements could be. The solution elements drawn from the interviews were categorised in four broad areas:

- Development of cross-sectoral care circuits structured by (overlapping) age cohorts and based on subsidiarity;
- Broadening of the service array, notably development of home and community-based services;
- Development of additional crisis and emergency capacity;
- Development of clear entry points to the system potentially backed up by a centralized registration system.

It is clear that there is considerable overlap between the suggestions offered by the interviewees and the proposals for interventions emerging from the roundtable discussions (as reported in the previous section). The call for a sectorally and cross-sectorally more integrated system and for a broadening of the service offer (notably in the direction of more home and community-based services) were distinctly heard in both cases.

Each of the four solution elements will now be discussed and supplemented with interview quotes. Quotes in the original language are in Appendix 6.

Development of cross-sectoral care networks

The diagnostic analysis has shown that sectoral and institutional fragmentation is at the root of the CAMHS system's inability to address the pressure it is confronting. The fragmentation manifests itself at both service and system (policy) levels. The awareness of the pivotal role of this fragmentation on the side of the medical professionals included in the interview sample translates into a plea for a more sectorally and cross-sectorally integrated CAMHS system. This entails a move from hospital-centric to regionally-managed care circuits. Psychiatric hospitals have an obvious role to fulfill in these networks but they do not have to be positioned as the network's functional and managerial hub. This implies that interviewed stakeholders do not see article 107 of the Hospital Law, which functions as the institutional basis for the reform underway in the adult mental health sector, as necessarily an appropriate basis for the reform of the CAMHS system.

Cross-sectoral integration entails that services are put in place to which not only mental health professionals contribute but, depending on locally defined needs, also youth care, schools, peer support and others. The 'outreach' experiments that have been put in place under the aegis of daycare centres since 2006 are considered to be valuable precursors.

- **[1]** "Demand-led and subsidiarity are key concepts. Subsidiarity means that care is provided at the least intrusive level. But that is only possible if you can manage the whole trajectory. When you do not have to say: I don't have those facilities in my trajectory. Demand-led

means that the needs are central, not the protocol. And it has to rely on genuine contact."

- **[2]**"I think that the hospital has a place, but in a network. Not in a structure that is made by itself."
- **[3]**"I think that the outreach model, which relies on a very intensive collaboration between a daycare centre and residential facility and the family situation or other services, is a very good model. I believe strongly in it, also because it appears to be able to avoid children ending up in residence."
- **[4]** "I fear that the hesitant attempts based on article 107 of the Hospital Law will never be able to get away from the existing institutional structure. The fact that every participating organisation in a network has to be able to trace, and in the worst of cases to recoup its own revenues is a big stumbling block for reform which has to rely on collective funds that are managed on area basis."
- **[5]**"A streamlining of the work does not have to be done by adding services, but maybe by cutting a few and having better staffed and better equipped teams. But then they have to commit to also deal with the complicated cases."

Broadening of the service array

Cross-sectorally integrated care networks have to be able to offer a comprehensive array of services so that they can function in a genuinely demand-led way. This means that young people do not have to conform to inadequate treatment simply because there is locally nothing else available. The broader service offering combined with clear accountabilities has also to put an end to the practice of 'passing the buck around', meaning that service providers try to avoid complex cases by forwarding these people to other services. Furthermore, the wider service array also implies that patients can be treated in the least restrictive, clinically justified environment. So, rather than to resort to a residential treatment by default (because outpatient services are as a rule weakly developed), children and adolescents can find treatment in less restrictive, more normal environments. Interviewees also refer to this as the principle of 'subsidiarity', meaning that, whenever possible, 'lower level' (less complex) home-based or outpatient services are relied on instead of costly and scarce residential services. Finally, services should to the maximum extent possible strengthen the young person's natural environment – family, peers and other supporters – in taking up an active role in care and cure.

- **[6]** "There it would be good to develop facilities that would help parents to work with their children. They would be accessible at convenient times, say late afternoon."
- **[7]** "Ideally a trajectory is made, with emphasis on outpatient services. However, in reality we see that services are quite limited. There is nothing for chronic patients – a young person that has to stay in a residential facility from 6 to 18 years old. Outpatient is quite limited. Day care is limited as well and outreach projects have only 2 full time staff. So, if you want to organise a concept of tailor-made care, these are the building blocks. There are gaps and imbalances."

Development of additional crisis and emergency capacity

The saturation of the mental health care system has been a prominent element in the diagnostic analysis. There are long waiting lists everywhere in the system, most conspicuously so for getting access to outpatient services. Particularly acute also is the lack of emergency and crisis facilities. Professionals, however, are aware of the fact that the waiting lists do not represent actual demand as people deploy demand-inflating strategies to get quicker access to the saturated care system. Also, in some cases demand will vanish when confronted with actual availability. (In this respect it is striking that a recently opened emergency facility within the KULeuven psychiatric hospital was not fully occupied after its first year of operation). Nevertheless, a lack of emergency and crisis capacity is acutely felt in the field and in response interviewees argued for the creation of supplementary, strong and multidisciplinary crisis facilities (including both psychiatric and broader youth care capabilities).

- **[8]** "Emergency situations need to be dealt with between youth care, emergency services of psychiatric hospitals and physical disability care. Multidisciplinary teams have to be created with representatives of all these agencies."
- **[9]** "If you leave people sitting with that crisis sentiment, then the problems become structural. If parents and children can be separated early on in the conflict and are allowed to work constructively with it, then many will quickly rebound."

Development of clear entry points to the system

Children and adolescent mental health professionals are concerned about the ill-structured access to the CAMHS system. This ought to be better structured by either streamlining the entry gates or by bolstering the mental health expertise at the various points of contact.

- **[10]** "Each age-based category ought to have a trajectory, with dedicated entry gates, first to the outpatient services, then to home-based, then day care and finally to residential services. The majority of youngsters ought to be serviced in outpatient care."
- **[11]** "There is an entry gate to the system, but who is staffing it? The most experienced professionals ought to be at the entry gate. Crisis call in lines are often manned by people who have just come from school. When I hear that I wonder what we are doing. But it is difficult to get experienced care providers to take up those kind of duties."

4.1.3. Solution elements from Part I of this KCE-study

Global overview on solution elements from KCE study Part 1

What transpires from the **international review** is that in the countries surveyed there has been a movement in recent years in CAMHS towards

- more resources for prevention;
- a better integration with basic youth care services;
- a more streamlined access to the mental health care system;
- a larger emphasis on outpatient services;
- a more rigorous outcome measurement.

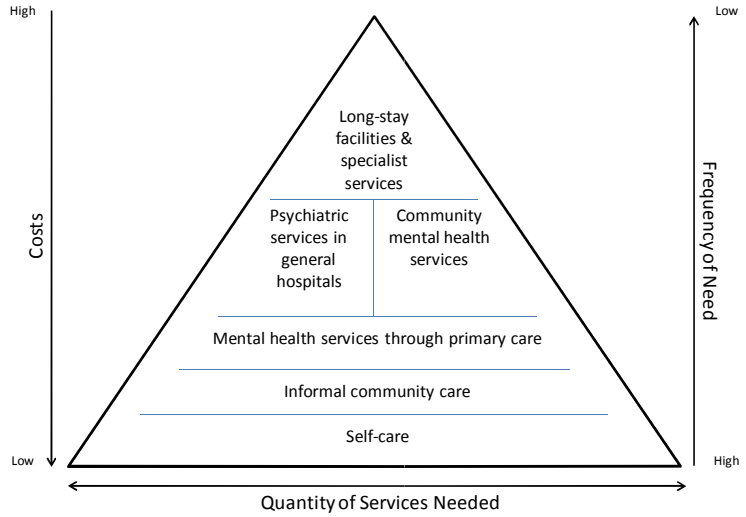
Specific care management solutions – such as the 'Children's Trusts' in the UK, the multidisciplinary youth care centres in Canada, and the 'shared access gate' in the Netherlands – are, however, difficult to assess in isolation from their wider national or regional context. One of the conclusions of the international comparison of the authors is that many difficulties are experienced with the practical implementation of the theoretical and ethically based frameworks on which the CAMHS reforms in these countries are based.[9]

The **peer-reviewed literature survey** focused on two influential models for the organization of mental health care for children and adolescents:

- the World Health Organisation (WHO) model,
- the 'System of Care' approach.

The WHO model highlights that a mental health system for children and adolescents consists of a mix of services. It is usually depicted as a pyramid, suggesting a hierarchy of services from generic, low-cost and frequently administered home and community-based services to specialized, expensive residential services in psychiatric hospitals for a small minority of complex cases (Figure 3). The model does not show how the mental health care system interacts with complementary youth care services in adjacent sectors. It is not a scientifically validated model either. For the purpose of developing a conceptual model it is, however, useful to keep the six basic types of services proposed by the WHO model in mind.

Figure 3: WHO model of recommended basic types of services in a children and adolescent mental health system



The 'System of Care' approach: importance for this report

Another model that is dominant in the peer-reviewed literature is the US-based System of Care approach.[2, 9]

The reasons why we zoom in on the System of Care[14] approach are multiple:

- System of Care is an exemplary embodiment of the principles of community-based care as they are increasingly embraced in mental health systems around the world.[9] The values and principles put forward by the National Council for Hospital Facilities[13] as a guideline for reform of the CAMHS system also cohere very well with the 'System of Care' approach (see discussion further in section 4.1.5.2).
- System of Care also provides a foil for evidence-based service delivery practices (such as 'wraparound' and 'multisystemic therapy') that are provided within the overall framework and value base of the 'System of Care' approach and do not perform optimally in a publicly supported service system outside of the context of an overall system infrastructure (see Part I of this study)[9].
- The scope of the System of Care approach matches the scope of the present study. It is a whole systems approach that envisages a coherent process of reform at the practice level, the local level and the state level to deal with the kind of interconnected problems pointed out in the diagnostic part.[14] The historical circumstances from which the 'System of Care' emerged, and the challenges it sought (and continues to seek) to address, are comparable to those that can be observed nowadays in Belgium (see inset box[20]).
- The literature review concludes that the evidence base in favour of the System of Care approach is promising but inconclusive; so this remains a caveat.[9]

In Belgium the System of Care approach has not yet been widely embraced.[42] However, it would be incorrect to state that there is no System of Care approach in Belgium, as elements of the approach can be pointed out in most mental health service systems. Its potential for making a positive contribution to systems reform in Belgium is likely far from exhausted.

Historical problems resulting in 'System of Care' concept[20]:

- **Little mental health care for children – large percentage unserved or underserved;**
- **Overuse of excessively restrictive settings (high costs, poor outcomes);**
- **Limited service options (outpatient, inpatient, residential);**
- **Lack of home and community-based services and supports;**
- **Fragmentation and lack of cross-agency coordination (parallel mental health systems across child-serving systems);**
- **Lack of interventions tailored to unique child and family needs;**
- **Lack or partnerships with families and youth;**
- **Lack of attention to cultural differences;**
- **Providers not skilled in state-of-the-art approaches and practices;**
- **History of poor outcomes.**

Introduction to the System of Care approach

The report of Part I of this study stresses that System of Care is not a 'model' to be replicated or a 'program' to be administered.[9] That means that in different communities, regions or countries that embrace a System of Care approach different organizational manifestations of this philosophy, depending on context, culture, and resources can be found. However, if it is a System of Care approach that is underpinning these different care systems the foundational principles will be the same. Indeed, what the System of Care approach offers is an organizational framework for systems reform based on a clear set of values and guiding principles. The System of Care framework has been likened to a Rubik's Cube, a well-known three-dimensional puzzle. For the puzzle to be solved, each of the six faces must be a single solid color. That can be metaphorically translated to the System of Care approach where six areas of attention have to fit together to come to a working system.[20] The six areas are:

- An overarching strategic approach to systems design underpinned by clear choices as regards target group, desired outcomes, and allocation of resources;

- A clear set of core values and guiding principles to guide the reform;
- An array of design components (from system oversight to coordination and delivery of services to outcome assessment) that are congruent with the basic strategy and core values;
- A practice approach that embodies the core values of a coordinated, individualized, youth-guided and family-driven system;
- An array of evidence-based services and supports;
- A coherent, long-term strategy for system change, leading from pockets of innovation to wide scale adoption of a new model and practice.

System of Care is nowadays defined as:

"a broad flexible array of effective services and supports for a defined multi-system involved population, which is organized into a coordinated network, integrates care planning and care management across multiple levels, is culturally and linguistically competent, builds meaningful partnerships with families and with youth at service delivery, management and policy levels, has supportive management and policy infrastructure, and is data-driven."[17]

Table 5 summarizes key elements of the 'System of Care' approach:

Table 5: Key elements of the System of Care approach

Target group: These are in the first place the children and adolescents themselves, embedded in their circle of family members and caregivers. The age cohort that is addressed by 'System of Care' is typically 0 to 18.	**Multi-level implementation**: the 'System of Care' approach is complex and implementation is a multifaceted, multilevel process at the level of the state, regions and local communities, and at the service delivery and practice level. Evaluation must measure both system-level and practice-level outcomes. System-level changes only will not suffice to improve child and family outcomes.[14]
Value base: 'System of Care' is grounded in a clearly articulated value base – the approach is youth-guided, family-driven, community-based and culturally and linguistically competent. A set of 12 guiding principles is based on these three basic values.[14]	**Financing**: Reform of mental health systems towards a 'System of Care' approach usually takes place in a setting of restricted funds. Therefore innovative funding[o] options need to be developed, including cross-sectoral 'braiding' of funds (from mental health, child welfare, juvenile justice, education and substance abuse), redeploying funds from higher to lower cost services and implementing case rates or other risk-based financing to increase flexibility.[17]
Services and supports: 'System of Care' encompasses a wide array of services, broadly categorized as supportive services, non-residential services, and residential services. There is an emphasis on natural, supportive services – including peer family support, respite services and supported housing - as these are often excluded from the mental health service offering.[14]	**Actors involved**: youth, families, care givers and providers of a wide array of services play a key role in operationalizing a 'System of Care' approach. In a wraparound approach these are assembled in a Child and Family Team. Part of the Team is a Family Partner who is someone with personal experience in caring for a child with mental health challenges. Family Partners help to engage the family, support and advocate for the family, promote collaboration between family and professional providers, and connect to natural and informal supports Typically there is also a Care Manager, who act as accountable manager for children and families with serious and complex needs, works intensively with small number of families (e.g., 8-10) and who has authority to convene Child and Family Team as needed. Service Coordinators assist families with basic to intermediate needs to coordinate services and supports. Usually they have other responsibilities, and/or assists large numbers of families. Care Management entities serve as the local or regional locus of responsibility and accountability for managing care and costs across systems for children with serious and complex issues who are involved in multiple systems and are "high utilizers" of services, often with poor outcomes. This entity may be a public agency, nonprofit, regional authority, collaborative or a partnership of agencies.[17, 20]
Practice approach: Wraparound is a team-based, collaborative process for implementing these kinds of services for children and adolescents with complex needs and forms an integral part of the 'System of Care' approach. Family-driven care means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community. Youth-guided means youth are empowered in their treatment planning process from the beginning and have a voice in decision- making. Cultural and linguistic competence makes sure that systems are able to serve children, youth and families from diverse racial, ethnic, socioeconomic, linguistic backgrounds. Integrated care focuses on one plan of services, even when multiple systems are involved, and supports the goals of continuity over time and across systems.[14]	

[o] It should be noted that the WHO warns against the abrupt transfer of financial means from the hospital sector to the outpatient sector.[9, 43] 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.[9, 43]

4.1.4. Solutions proposed by other KCE-reports

Therapeutic Projects

In 2006, the Minister of Social Affairs and Public Health launched a program seeking for alternative organization models in mental health care by means of the development of experimental "therapeutic projects". Therapeutic projects are intended to implement an 'integrated health services model' in clearly defined catchment areas, providing services adapted to the needs of the patient and promoting his rehabilitation in society and guaranteeing continuity of care. The target population are patients with 'chronic and complex mental disorders' within pre-defined clusters (i.e. 'children and adolescents'; 'adults'; 'elderly'; 'substance abuse'; 'forensic psychiatry'). Each project should include as participants at least: (a) a psychiatric hospital or a psychiatric unit (b) a specialist ambulatory mental health centre or one of the "pilot projects" (home care or outreach), funded through the Ministry of Public Health and (c) a primary care partner (an association of general practitioners, Integrated Services Home Care, Home Services).

The plan and implementation process of the therapeutic projects were evaluated by the KCE using qualitative study methods (i.e. document analysis, interviews and focus groups).[11] Some key learning points that emerged during this evaluation process are listed below:

- The government(s) should stimulate innovation in mental health care on a continuous basis by more focused and structural embedded strategic programs. This requires collaboration and fine-tuning of policies between the different competence levels. A permanent interministerial unit (supported by a scientific staff) could be established to give strategic advice and with dedicated resources to actively guide this process. During this process it is important that the government communicates its policy framework and its intended objectives in a clear, coherent, consistent and continuous way to the sector;
- The bottom-up approach, which called for partnership proposals from the sector is well appreciated by the sector. In contrast to this general positive appreciation, it appears that the sector experiences difficulties in setting up effective organisational and management practices to develop interagency collaboration;
- The coordinator is seen as a crucial node in the functioning of the partnership. The role of coordinator should, however, focus more on stimulating, facilitating and supporting collaboration than on taking on all the administrative tasks that are attached to this collaboration;
- The integration of the primary care sector is not realised in the majority of the therapeutic projects. The mentioned issues are resources to participate, mental health care competencies, cultural differences between primary care and the psychiatric sector, the difference of mobilizing umbrella organizations versus individual GPs. To reinforce a care model that provides care in the least restrictive environment it is required to strengthen the participation of the primary care sector in mental health care;
- The financing mechanisms that are implemented to stimulate interprofessional collaboration should include a certain degree of flexibility to allow that the collaborationis adapted to the evolving patient needs;
- A better understanding in how patients and family can be involved efficiently in this interprofessional collaboration process is needed;
- The aspect of professional secrecy and sharing of information has to be handled before to launch interprofessional collaboration, in order to avoid fundamental barriers in the collaboration;
- There is a clear need to evaluate integrated health services models. This evaluation should not only focus on the policy- and organisational level but should also include the impact of these models on social participation and well-being of patients. This will require the prospective colllection of patient data that are used to evaluate performance in a scientific manner.

Psychiatric emergency care

In 2010 the KCE published a report entitled 'Emergency psychiatric care for children and adolescents', a study that aimed to examine to what extent emergency psychiatric care in children and adolescents in Belgium needs to be developed and if so, how it should be organized.[10] The methods used were a literature study, a secondary data-analysis (i.e. MPG/RPM; MKG/RCM) and stakeholder input (nominal group techniques & focus groups).

Although several authors express the **need for a clear definition** of psychiatric emergency in children and adolescents, only a limited number of authors address the issue of definition in their papers. Those that do explicitly address the topic of definition, point out that a distinction needs to be made between the concepts “emergency” and “crisis”. An **emergency** is life-threatening requiring an immediate life-preserving response whereas a **crisis** is not life-threatening and requires an urgent response to prevent deterioration. The level of danger (i.e. harming oneself or others) involved will determine whether the emergency care or crisis intervention needs to occur in a (non-)residential setting.

The literature study illustrated that the majority of children presenting to psychiatric emergency services are between **6 and 18 years** old. Suicidal ideation or suicide attempts and behavioral problems were the most common reasons for (child and) adolescent psychiatric emergency services presentations. The available **literature that evaluated the effectiveness** of different organizational forms of psychiatric emergency or crisis services is **scarce** and suffers from methodological limitations. Nevertheless, there is a clear trend in the literature for complementary models of intensive psychiatric care provision including intensive outreach services, crisis intervention teams and age-appropriate day patient and inpatient provision.

Focus group results confirmed these literature findings. Participants agreed that both residential and non-residential care should be available, but that **taking the child out of its natural environment is not preferred** and should be considered as the last option. The participants further stipulated that investing in emergency psychiatric care is necessary but has to go hand in hand with large investments/reforms that ensure a more effective regular offer (child welfare and health care) for children and adolescents.

The secondary data analysis of the current registration systems (i.e. MPG/RPM; MKG/RCM) pointed to **a lack of systematic accessible registration systems**. Therefore, the precise estimations of the availability and utilization of emergency psychiatric care was not possible.

Based on the different elements studied the KCE formulated the following **general recommendations:**

- to conceptualise emergency psychiatric care as separate “function”, rather than as a specific service/department with a priority on non-residential care;
- to embed the development of emergency psychiatric care in a larger policy framework that guides the reform of the entire cams system;
- to coordinate at the policy level the different activities and financing mechanisms between the different competency levels in Belgium;
- to operationalize the emergency psychiatric care at the loco-regional level in the development of financial and collaboration agreements between the different types of care providers involved in CAMHS;
- to organize services in order that they are immediate accessible (24h/24h; 7/7) with the injunction to refuse children and adolescents without an appropriate assessment of the situation;
- to prioritize non-residential care as close as possible to the natural environment of children and adolescents but also to provide (highly secured) beds within psychiatric child and adolescent units (i.e. K) with a supportive function;
- to link the “emergency function” in one way or another to existing (hospital-based) emergency services since these services are well known entry gates.

4.1.5. Solution elements proposed by the National Council for Hospital Facilities

In section 3.4 the key elements of the diagnostic assessment of the ad hoc group to the permanent committee ‘Psychiatry’ of the National Council for Hospital Facilities have been briefly reviewed. These insights have been the basis for a set of recommendations that offer a reference framework for pilot projects to guide the reform of the children and adolescent mental health system.[13]

The recommendations by the National Council for Hospital Facilities

The recommendations will be summarised below. For more details the original advice paper can be consulted:

- The National Council champions a move towards an accessible, multisystemic and strength-based care system. This means that services are not only narrowly oriented towards the child in isolation,

but encompass the young person in its variegated context (including families and schools). Services have to be provided, in so far as it is medically and practically justified, in the child's normal environment. Care capitalises on the available strengths and positive drivers present in the child and its environment, with the ultimate aim to help the young person to maximally participate in society.

- Mental health care for children and adolescents has to be based on the subsidiarity principle: care has to be provided in the least restrictive environment that is justified, relying on residential treatment only when it is really necessary and for the shortest duration possible. This has to be supported by a strengthening of outpatient service capacity, crisis and emergency facilities and in mobile 'assertive care' (the latter refers to flexible psychiatric care in the natural environment for youngsters with complicated difficulties).
- Coordination between different mental health services and adjacent areas needs to be strengthened in order to provide a regionally-based 'total care package'. Mental health services need to be incentivised to lend their expertise where it is needed in youth-oriented basic care facilities. Vice versa, care givers and educators in adjacent sectors need to be supported in developing their mental health oriented skills. The psychological and psychosocial function in paediatrics needs to be reinforced.
- Prevention, detection and early intervention pay significant dividends, particularly in the case of young people. Promising initiatives in this area – particularly those that target the parent-child nexus - need to be consolidated and expanded.
- The National Council envisages a CAMHS system that consists of 6 key functional modules:
  - A (semi-) residential care function;
  - An outpatient service function;
  - A prevention, detection and early intervention function;
  - A crisis, emergency and assertive care function;
  - A function that liaises with home and community-based (after) care services;
  - A number of specialised care modules for specific target groups (addiction, young delinquents).

The National Council of Hospital Facilities' recommendations considered through a 'System of Care' lens.

The National Council's recommendations regarding the basic approach and values for CAMHS are summarized below (Table 6). Congruence with the system of care philosophy and approach is brought into relief by associating relevant System of Care principles in the right-hand column.

From the above it appears that the National Council's advice is in spirit quite close to the 'System of Care' approach. However, there are a number of areas in the National Council's paper that need increased specificity and/or clarification:

- Services recommended to address deficiencies do not constitute a comprehensive array of services and supports (focus on emergency, crisis, and assertive care).
- The envisaged system seems to rely on 'traditional' disciplines – child psychiatrists, psychologists, social workers, nurses, educators. Creative approaches may be needed to create a broader provider network to fill current gaps and re-tooling of current providers to develop skills needed for current system needs within the new framework.
- There seems to be some confusion of 'intensity' and 'quality' of services with 'beds' throughout the advice. The advice seems to equate the number of beds with quality, and may imply that treatment at high level of intensity equates with inpatient/residential treatment. A system must comprise a balance of services and supports (home and community-based, inpatient, residential, supports, etc.). The need for beds declines when there is a comprehensive array of home and community-based services that are sufficiently intensive.
- The advice suggests that different approaches are needed for early childhood and transition age youth. This is questionable. There are different partners and different interventions for these groups, but the same overall philosophy, values, structures is likely to apply across the various age groups.

Table 6: Comparing recommendations of NCHF advice with 'System of Care' principles

Recommendations by the NCHF	'System of Care' principles
Goal: Maximum possible participation in society, recovery	improved functioning in home, school/work, community, throughout life.
Necessary to respond flexibly through community care and formal and informal services, even provided at home	home and community-based services
Focus diagnosis and treatment at the family level; serve children and adolescents in the context of their families	family focus
Address the challenge of cultural awareness in CAMHS tailored to emerging diversity and increasingly complex society; address geographic and other disparities	cultural and linguistic competence and eliminating disparities in care
Strengthen community-based (ambulatory) services and specific modules of emergency, crisis, and "assertive" care	comprehensive array of services and supports, ecological approach, address all life domains
Provide mental health care as much as possible in normal living environment, least intrusive/restrictive environment; global and ambulatory as possible; use inpatient only as appropriate and for short lengths of stay	least restrictive setting
Ensure effective services; incorporate scientific research and innovation in care	effective, evidence-based practices
Better connect inpatient, residential, home and community-based services; liaison and consultation across youth sectors	coordination at service delivery level
Implement a multisystem approach; regional collaboration within mental health and among departments	cross-system collaboration
Address two poles of the age continuum – early childhood and transition age youth;	developmental spectrum
Focus on the prevention of severe disorders; need for screening, early identification/intervention	promotion, prevention, early identification/intervention – public health approach
Quality care; performance indicators; subject to evaluation and scientific research	accountability, continuous quality improvement

4.2. Root definition

4.2.1. General shape of the root definition

The insights emerging from the diagnostic analysis (bottlenecks and friction points in the existing system that need to be avoided) and from the discussion of the solution elements can be consolidated in a 'root definition' of the envisaged mental health system for children and adolescents. We want to stress that the perspective taken here is conceptual, not organizational. In other words, the root definition does not capture the mission of one given monolithic organization but expresses the purpose of an idealized system that can be organizationally embodied in many different ways and involving many actors.

Hence, a root definition, as discussed in section 2.1.2, is a synthetic expression of the fundamental contribution (or 'purpose') of such a care system. It is a precise statement that takes the following generic form: "The envisaged Belgian CAMHS system is a system owned by O and operated by A, to do X by Y to customers C in order to achieve Z within constraints E."

The care system's purpose is expressed by the root definition's core assertion: "The envisaged Belgian CAMHS system is a system to do X to clients C in order to achieve Z."

The Y elements specify *how* this purpose is realised.

Additional qualifications provide a richer framing of the basic purpose:

- Actors A: people and organizations that are involved in actually implementing the system's purpose;
- Owner O: actor(s) who are able to change or stop the system and therefore can be regarded to own it;
- Environmental constraints E: external circumstances that influence the system's operations;

4.2.2. Core purpose

We will now proceed by proposing a formulation for the core purpose of the envisaged mental health care system for children and adolescents in Belgium:

"The CAMHS system offers an array of services (X) for children, adolescents, and young adults with or at risk of mental health challenges, and their families (C), to help these young people to function better at home, in school, in the community and throughout life (Z)."

Delivering services (X)

The CAMHS system is basically there to deliver 'services'. These services encompass the whole spectrum from 'prevention' to 'cure' to 'care' to 'recovery' (as proposed by the National Council advice, see section 4.1.5). The WHO proposes a typology of six services, ranging from 'self care' to 'long stay facilities and specialist services' (section 4.1.3). The System of Care approach makes a distinction between three broad categories of services: supportive services, non-residential services, and residential services (section 4.1.3). The roundtable discussions and interviews have confirmed that participating stakeholders see the remit of the CAMHS system go beyond the sphere of specialized mental health services ('cure') to encompass 'care'-oriented services and promotion and prevention (sections 4.1 and 4.2).

Beneficiaries (C)

The 'clients' of the system are young people and their families. The system potentially delivers services to all young people: those with identifiable, more or less severe mental health challenges and those who are at risk of being confronted with these disturbances.

The National Council advice sees prevention, directed towards the general population of 0-18 year old people, pertaining to the basic care package offered by the CAMHS system. In addition, it outlines progressively more specialized and involving services for youth with more complex problems.[13]

The System of Care approach segments the total population of young people that can benefit from mental health services in three groups depending upon the intensity of their needs (from no or very basic needs to

intermediate to complex needs that require intensive mental health supports; section 4.1.3.2).

It was agreed by the stakeholders participating to roundtables that the CAMHS system in principle ought to help all children in developing their psycho-social abilities, whilst the core finality of the CAMHS system (providing care) is focused on children with difficulties. (It is a matter of policy to decide how the available resources will be allocated to the general population versus youngsters with mental health problems).

The scope of the services being delivered by the CAMHS system, however, extends beyond the child or adolescent in isolation. Stakeholders have indicated in roundtable discussions and interviews that the existing mental health care system is too child-centered and that it does not involve the family and the environmental context in which the child functions (i.e., school and community) enough (sections 3.1 and 3.2). This is an element that is much less conspicuous in the National Council advice. The System of Care approach, however, is emphatically youth-guided and family-driven, meaning that families to the extent possible are involved as partners and co-decision makers in developing care trajectories.

Outcomes (Z)

The ultimate aim of the services delivered to these young people is to increase their wellbeing and their potential for development, throughout their life. That does not mean that clinical outcomes are not important. But the ultimate aim goes beyond the improvement of the young persons' situation in a merely technical sense. The National Council's advice is very much in agreement with this. It states that 'recovery or integration' and the 'maximum achievable participation to society' have to be the ultimate aim of care provision.[13] The definition of the System of Care approach is in agreement with the core purpose included in the root-definition above. Also amongst the stakeholders who participated in the roundtable discussions there was a consensus that the system ought to be oriented in the first place towards responding to the needs of young people with mental and behavioural problems. Stakeholders were keen to avoid a too 'functionalist' language to refer to these outcomes but stressed the importance of 'wellbeing' and 'development'.

4.2.3. Additional qualifications

The core of the root definition is now supplemented with additional qualifications: how is the purpose realized (Y)? who are the actors involved (A)? who 'owns' the system (O)? And what are crucial constraints in which the system has to operate (E)?

Modus operandi (Y)

The notional CAMHS system delivers services. What is, however, distinctive about the system is the way in which these services are delivered. We propose to include 9 qualifiers in the root definition that specify how the system should function. Throughout references are made to the National Council advice,[13] the System of Care framework,[14] and Part I of this study.[9]

Ethically guided

In a work system that basically revolves around the suffering of the child, professionals need clear ethical guidelines to navigate the many tensions and dilemmas surrounding the child. These values are a necessary (but not sufficient) condition to contribute to the wellbeing and development of the young person. The System of Care approach emphasizes a strong value base anchored in the rights of child, stressing accessibility and personalization of services and the empowerment of children and families to take responsibility in their own care trajectory. The National Council advice also stresses the strength-base and accessible character of services, but is more reticent about the role of the family.

Professionally supported

Projecting the scope of the CAMHS system beyond specialised care and putting greater emphasis on home and community-based services does not mean that anyone can be designated as care provider. In the roundtables it was brought forward that provision of care in the broad sense remains in all circumstances linked to having the requisite expertise. The National Council advice dedicates a separate chapter to the widening gap in skills and recommends, amongst others, that outreach work needs to be rewarded and care givers and educators in adjacent sectors need to be supported in developing their mental health oriented skills.

Evidence-based

Evidence-based practice is stressed as an important value in the international CAMHS-literature.[14, 15] Roundtable discussions revealed that there seems to be sensitivities around the importance of providing mental health care services in an evidence-based way. The controversy is centered more on the 'evidence-based' discourse (which some see as ideological and commercially-motivated) rather than on the principle that scientific evidence is relied on to the extent possible in developing effective care. The National Council advice confirms the importance of scientific evidence in moving towards novel care concepts. There are innovative programs, services and care programs that are not yet proven effective but show promise and/or are believed to be helpful in meeting outcomes important to children, adolescents and their families. The term evidence-based should provide space and support (e.g. research programs) for these promising approaches as to avoid fears that professional authority and the potential for innovation will be undermined by the requirement to stick to strictly scientifically validated protocols.

Co-ordinated

Fragmentation within the CAMHS sector (e.g. between residential and outpatient services) and between the mental health and adjacent sectors has in the diagnostic analysis been identified as one of the key problems undermining the efficiency and effectiveness of the current mental health care system for children and adolescents. In addition, isolated initiatives that are established to respond to acute local needs are not integrated with other mental health and youth care services. Hence improved 'co-ordination' is one of key requirements for the envisaged CAMHS system. The advice of the National Council is very much in support of this and argues for more effective collaboration between inpatient and outpatient services. It also proposes an important 'consult and liaison' function to ensure the co-ordination with adjacent sectors. The international review in Part I has shown that in all countries surveyed there has been a move towards a higher level of co-ordination between mental health services and also between mental health and basic youth care services. Also in the interviews and roundtable discussions the argument for better co-ordination was clearly put forward. The 'System of Care' model is predicated on a personalized approach, where the services are wrapped around in an individual in a co-ordinated way. Finally, it is also worthwhile to observe that the reform that is currently underway in the Belgian adult mental health sector is very much driven by the goal to better co-ordinate outpatient and residential services.[44]

Networked

The establishment of care networks is one way to provide an organizational context for better co-ordination between services. Care networks are (usually) regionally-defined clusters of different care providers – spanning the spectrum from basic youth care to specialised, residential facilities – that co-ordinate their activities for the support of one or more care trajectories. Again, networks have been a prominent feature in the reform of the adult mental health sector (these concepts have been legally enshrined in art. 11 of the Hospital Law).[3]

Personalized

It is particularly the 'System of Care' approach that argues for a personalized (or 'individualized') way of providing care, particularly for young people with complex mental health challenges[p]. 'Wraparound' brings together natural, supportive services, basic youth care and specialized mental health care in flexible and customized constellations. Personalization is then an incentive for sustaining collaborative and co-ordinated care networks.

The National Council advice argues for a 'multi-systems approach' based on an individualized diagnostic and care plan.

The interviews reveal a more general concern related to personalization. It is recognized that mental health care is too often guided in ad hoc way by capacity and services available rather than by the needs of the young person and family.

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[p] The meaning of the term 'personalization' in this report (understood as 'customization', i.e. adaptation to individual needs) has no direct relationship with the 'personalisation agenda' as it is pursued for example in UK health care. This is a strategy to give service users choice and control over the care services they receive through, amongst others, direct payments and personal budgets (http://www.communitycare.co.uk/Articles/19/08/2011/109083/personalisation.htm).

Developmentally appropriate

One of the key aspects that distinguishes the child and adolescent mental health system from the adult system is that the young person develops constantly and rapidly. Interviews and roundtable discussions have stressed that it is important to take this developmental perspective into account when developing and providing services to young people.

Culturally competent

Services have to be delivered in a culturally competent and linguistically sensitive manner. This means that care providers know how to address the patient in his/her language and take into account cultural sensitivities. It is a key element in the principles that guide the 'System of Care' approach. In the diagnostic analysis this has not been a prominent theme (although stakeholders working in the Brussels area point out that the lack of culturally competent and multi-lingual staff compromises the capital's mental health services' effectiveness and efficiency). The National Council advice confirms that care in so far as possible has to be provided in accord with prevailing social and environmental conditions (and it holds forth that acting to reduce existing inequalities belongs to the remit of public authorities).

Provided in the least restrictive environment

Services are provided in the least restrictive, clinically-justified environment possible. This is an alternative way of stating the 'subsidiarity principle' that has been referred to earlier in this report: whenever possible, 'lower level' (less complex) home-based or outpatient services are relied on instead of costly and scarce residential services. It overlaps with the requirement for a greater emphasis on community-based services. This notion has been supported by interviewees and discussants at the roundtable. Also the National Council advice is very much in support as it argues for a shift of the system's center of gravity towards outpatient facilities. The reliance on care that is provided in the least restrictive environment is also a core tenet of the 'System of Care' approach.

Note that **what has not been withheld** as a constituent part of the root definition is the 'family-driven' aspect that is very prominent in System of Care. The participatory process has shown a significant degree of agreement on the fact that mental health care needs to focus on the child in its social environment. However, stakeholders involved in this study, point out (at the validation and consolidation workshops; see Section 4.5 and 4.6) that the relationship between children that need care and their families are not always without conflicts and complications. Families can be dysfunctional and/or they can be part of the youth's problem. The 'System of Care' approach is quite clear in its focus on a genuinely family-driven model, meaning that family members (and other caregivers in the child's social environment) are to the extent possible and appropriate mobilized as partners in care. The National Council advice remains noncommittal on this issue (the world 'family' is only mentioned twice in the whole memorandum).

Actors (A)

It has already been stressed that the root definition articulates a purpose and a general modus operandi of a conceptual, idealized system. The way in which this notional system is organized is, at this stage, still an open question. However, it is clear that the general purpose encapsulated by the root definition will have to be realized by the contributions of many different actors. There will be contributions of specialist mental health professionals but also of many other parties. This is a non-exhaustive list of parties that could potentially contribute to a CAMHS 'work system': mental health services, social services, educational services, (somatic) health services, disability services, substance abuse services, vocational services, recreational services, juvenile justice services, children and youth, their families and other caregivers. The stakeholder mapping will provide an insight how these parties may contribute to the CAMHS work system (Section 4.4.).

Owner (O)

As the Belgian mental health care system is funded by both federal and federated entities, they are able to stop or change the system. The envisaged CAMHS system can therefore be considered to be mandated by these authorities.

Constraints (E)

From the evidence base discussed earlier it transpires that a limited budget, significant institutional and sectorial fragmentation and an increasingly stressful post-industrial society are circumstances that will continue to exert an important influence the CAMHS system's operations.

Expanded root definition

In light of the qualifications added above, the root definition can now be put forward as follows:

"The CAMHS system is an array of ethically guided, professionally supported and evidence-based services for children and adolescents with, or at risk of, mental health challenges and their entourage, that are provided in a co-ordinated, personalized, developmentally appropriate, and culturally competent manner in the least restrictive environment that is clinically appropriate and most adapted to the child's needs, to help these young people to increase their wellbeing and potential for development, at home, in school, in the community and throughout life."

4.2.4. Transformations achieved by the CAMHS system

The purpose of the envisaged CAMHS system is to increase the wellbeing and potential for development of young people with (or at risk of) mental health challenges to function better in society. This can be considered to be the basic transformation that the system ought to achieve at the child, youth and family-level. Following the distinction between service and system level outcomes in the 'System of Care' approach,[14] we also specify the transformation to be achieved at these levels together with the kind of criteria that can be used to evaluate the performance of the system at the various levels.

Child, Youth, and Family-level Transformation

Children, adolescents, and young adults with or at risk for mental health challenges and their families function better at home, in school, in the community and throughout life.

The operation of the system is judged based on criteria of effectiveness,[12] i.e.

- improved wellbeing and fulfillment of child/adolescent;
- improved clinical outcomes (improvement in symptoms);
- improved functional outcomes (improved functioning in home, school, law enforcement domains);
- increases in behavioral and emotional strengths,
- improved family youth engagement/involvement;
- improved family functioning and reduced family burden.

Service-level Transformation

Child and adolescent mental health services and supports are coordinated and efficient.

The operation of the system is judged based on criteria of *efficiency* i.e. degree to which the system operates within human, financial and infrastructural resource constraints.[12]

System-level Transformation

The CAMHS system is evidence-based, resilient and capable to deal with the evolving requirements and needs of contemporary society and considers families and young people as partners in care.

The operation of the system is judged based on criteria of *ethicality*, *professionalism* and *adaptiveness*, i.e.:

- fidelity with value base (youth-guided, family-driven and focused);
- degree to which the system is able to learn and evolve with changing demands;
- degree to which it incorporates best available evidence.

4.3. Activity model

With the root definition in place, there is a basis for the development of an activity model. As explained in the Methods section, an activity model is a visual and synthetic representation of a work system that exists to achieve a particular purpose (see section 2.1.2).

As the term suggests an activity model shows activities, and their logical interdependencies, to be carried out by individuals to realise the system's purpose. From that perspective the model, despite its abstractness, corresponds with a very tangible reality of individuals spending time and energy in doing purposeful things.

Although the visual syntax of boxes and arrows may suggest the logic of an organigram, the conceptual model does not represent an organization. The boxes contain verbs, not names. As indicated before, it is very likely that people belonging to a range of different organizations and services will contribute to those activities. So the boundary delimiting the activity model is not an organizational boundary.

An activity model is not a process flowchart either, depicting how individuals (patients) move through the system from identification through diagnosis, treatment and release.

4.3.1. Functional modules

The model is composed of 35 different activities, grouped in 9 functional modules:

- Plan, provide and coordinate care;
- Manage access/entry into care;
- Provide crisis/emergency response services;
- Develop and support service array;
- Support families, other caregivers and youth as partners in care;
- Conduct prevention and life skill development activities;
- Conduct early identification activities;
- Develop and refine care model;
- System management and quality improvement.

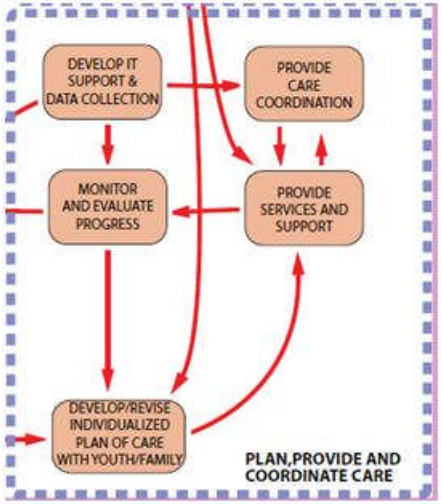
Each will be briefly discussed in turn, together with the constituent activities:

Plan, provide and co-ordinate care

Following the root definition the CAMHS system is a system that delivers services. Hence, there is a core module in which mental health services are delivered. The module does not indicate what kind of services are delivered and where. There are 5 constituent activities. The red arrows denote logical interdependencies, meaning that an activity at the head of the arrow depends on the tail end activity having taken place:

- **Develop/revise individualized plan of care with youth/family**: in the case of a child or adolescent that is helped by a straightforward treatment at, for instance, an outpatient center, this activity will not require a lot of time or resources. In more complex cases which require a wraparound approach, for example, this will take more effort.
- **Provide services and support**: this is the actual delivery of services. They can be simple and of short duration, or complicated and more persistent. Services can be delivered at home, at school, at youth care or outpatient centres, or in specialized facilities at psychiatric hospitals.
- **Provide care coordination**: the root definition puts forward the requirement that service provision is coordinated within and beyond the mental health sector. This requires dedicated resources so that people are able to spend time contributing to that activity. It is possible that in some cases people will choose to create specific organizational forms to support this activity, but that is beyond the scope of the activity model.
- **Develop IT support and data collection**: coordination will depend on at least some information management. This can be supported with a simple spreadsheet or by more sophisticated protocols. Again, the technical and organizational infrastructure to support these activities will be discussed later in the report.
- **Monitor and evaluate progress**: the provision of care services to youngsters and their families has to be monitored for effectiveness. This activity generates a necessary feedback signal that gives professionals and youth/family a basis to decide on the nature and extent of the care trajectory.

Figure 4: Plan, provide and coordinate care module

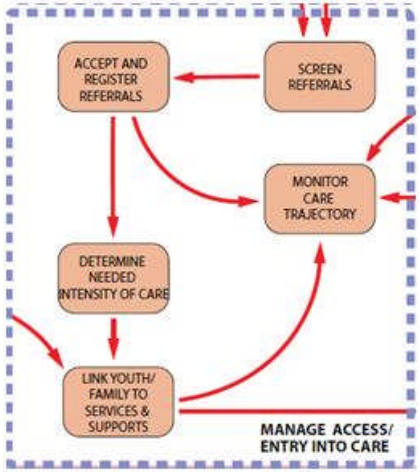


Manage access/entry into care

Prior to receiving care, children and adolescents have to gain access to the care system. There is a functional module that governs this access. It is supported by 5 distinct activities:

- **Screen referrals**: children and adolescents may seek mental health care services via different routes (emergency or crisis facilities, schools, general practitioners or paediatricians, etc). Whatever the route, at entry they have to be screened on the basis of an accepted protocol.
- **Accept and register referrals**: the screening will dictate whether the young person can be admitted to receive mental health services. If so, the person is registered. Whether this is a central registration or not the activity model does not specify.
- **Determine needed intensity of care**: after screening and registration an assessment has to be performed of what the needed intensity of care is.
- **Link youth/family to services and supports**: depending on the assessment of needed intensity of care the child/adolescent and family will be connected to appropriate services. Ideally, in consonance with the root definition, these services will be easily accessible, personalized, culturally competent and provided in the least restrictive environment possible. This activity connects then with the 'develop/revise plan of care' activity which is part of the care provision modules.

Figure 5: Access/entry into care module

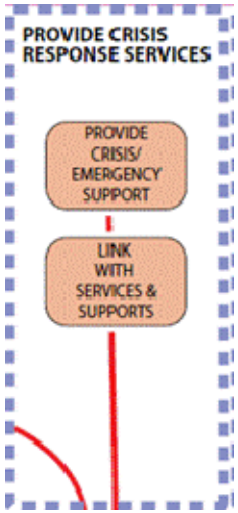


The two modules discussed above form the service provision backbone of the CAMHS system. However, they need to be complemented with other functional module for the system to work in accordance with the purpose and requirements laid down by the root definition.

Provide crisis/emergency response services

The lack of crisis/emergency response capacity has been pointed out in the diagnostic analysis as an acute problem. Also the National Council advice strongly recommends to allocate more resources to this function.[13] In the activity model, crisis and emergency response services have been located in a separate module, with 2 basic activities:

Figure 6: Crisis Response Services module



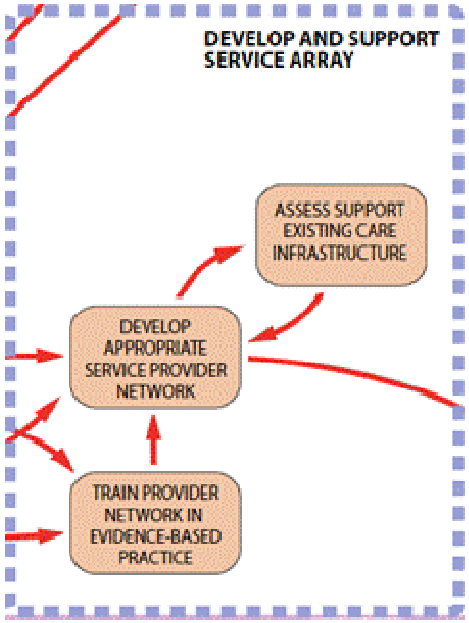
- **Provide crisis/emergency response**: the services have to provided. The activity model does, however, not specify how this has to happen (via mobile teams or via dedicated units in community mental health care centres or psychiatric hospitals).
- **Link with services and supports**: again there is need for a liaison function that connects to the 'manage access' module.

Develop and support service array

Services can only be provided when they are developed and supported. It has been observed in the diagnostic analysis that the service array that makes up the current mental health care system is too narrow. Mental health care services are too reliant on residential infrastructures. The National Council advice proposes a shift towards outpatient services. 'System of Care' wants to complement inpatient and outpatient services by natural, supportive services for youth and families. Whatever the mix of services and associated provider network that is deemed adequate in a certain (geographical) area, people have to spend time and effort to develop and support it. The module consists of 3 activities:

- **Develop appropriate service provider network**: again how this development activity is organisationally supported is beyond the scope of the activity model.
- **Assess support of existing care infrastructure**: development of alternative services rests on a gap analysis between the nature and quality of services and infrastructures already present in the area and the nature of the demand for services.
- **Train provider network in evidence-based practice**: whatever the nature of the mental health services, they have to be professionally supported (as put forward by the root definition). This may require more or less specialized training.

Figure 7: Develop and support service array module

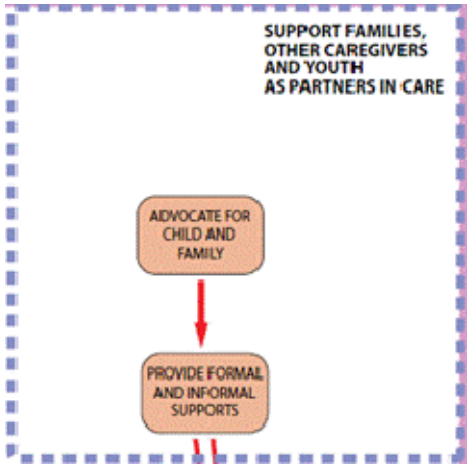


Support families, other caregivers and youth as partners in care

A family-driven care system relies on families and other caregivers to take up an active role in shaping and delivering the care trajectory. They have to be supported in doing so. The module consists of 2 activities:

- **Provide formal and informal supports**: the Families have to be supported with information, coaching, peer support, respite services and other formal and informal services in taking up that role.
- **Advocate for child and family**: the development of this supportive service offering has to be driven by energetic advocacy on behalf of children with mental health problems and families as caregivers.

Figure 8: Support families, other caregivers and youth as partners module

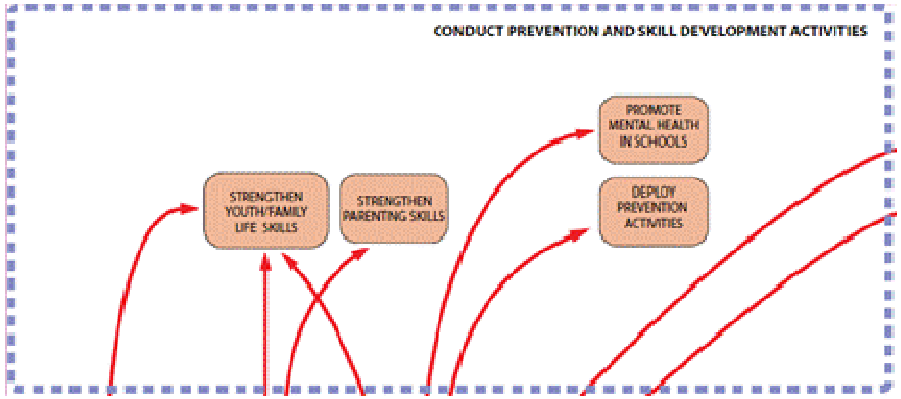


Conduct prevention and life skills development activities

The international review in Part I of this study[9] has shown how in the countries surveyed there has been a consistent move towards more emphasis on prevention. In addition, the narrative review showed that preventive programmes or early intervention in schools may have a positive effect on the prevention of anxiety and the development of self-confidence.[9] Also the National Council advice considers 'prevention and early identification' as one of the basic functional modules in its vision on the CAMHS system.[13] Similarly, the 'System of Care' approach gives a central place to the link with prevention activities.[14] The prevention and life skills development module in the activity model consists of 4 activities:

- **Deploy prevention activities**: this is the core prevention activity with which many different kinds of intervention in various settings may be associated.
- **Promote mental health in schools**: this is a health promotion and prevention activity especially focused at educators and children in schools.
- **Strengthen youth/family life skills**: a more stressful and demanding life in contemporary society (pressure to perform, pervasive technology, consumerism, etc) requires appropriate life skills of both children and families to reduce the vulnerability to
- **Strengthen parenting skills**: interviewees have pointed out that parenting skills are being eroded, increasing the vulnerability of children to mental health problems.

Figure 9: Prevention and skill development activities module



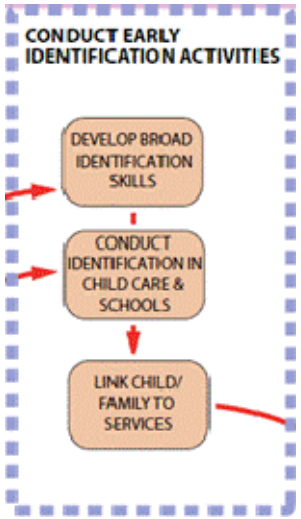
Conduct early identification

There is broad agreement that early identification of mental health problems is particularly important for children as timely intervention may have a very important impact on their development and on the child's and their family's quality of life. Also the National Council advice argues that

early identification is important in avoiding curative interventions later on in life.[13] Early identification activities have been included in a separate module of the model. This connects with the 'access management' module and onwards to the 'planning and provision of care' module. There are 3 self-explanatory identification-related activities:

- **Develop broad identification skills**: these skills have to be developed in parents, nannies, educators, and counceling staff in child care and schools.
- **Conduct identification in child care and schools**: this activity concerns the actual screening of children.
- **Link child/family to services**: Depending on the results of the screening, early identification services have to liaise with the mental health care system.

Figure 10: Early identification activities module



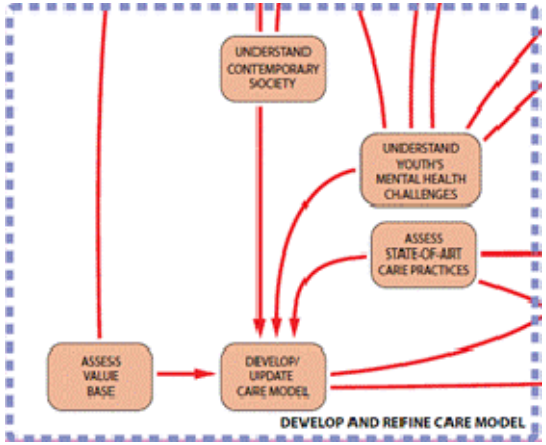
Develop and refine care model

The roundtables have clearly indicated that it is important for the CAMHS system to have a capacity for learning and self-repair. In other words, a capacity must be embedded in the system to adapt itself and refine the espoused care model in the light of developments in society, in expectations with regards to children, and in the mental health care practice. Five activities are included in the module:

- **Develop/update care model**: this is the central activity in the module. It is a reflexive questioning and adapting of the mental health care model for children and adolescents against the background of an evolving society and mental health practice.
- **Understand contemporary society**: the care model will have to reflect and respond to dominant social trends in society. People in the CAMHS system will have to spend time, however informally, in making sense of these developments.
- **Assess value base**: a care system reflects a particular value base (as does the present exercise). There has to be a regular assessment of the relevance of these guiding values and their capacity to inspire health professionals and policy makers.
- **Understand youth's mental health challenges**: youth's mental health problems are a dynamic datum. Society evolves as does the acuity of scientific methods to understand what is going on in young people's brains. Keeping abreast of these developments obviously requires dedicated resources. This activity also feeds into the early identification and prevention activities in other modules.
- **Assess state-of-the-art practices**: Similarly, research is needed to assess novel developments and techniques in the practice of mental health care.

Again, the activity model makes no assumptions about the precise organizational way in which this 'develop and refine care model' module is embodied.

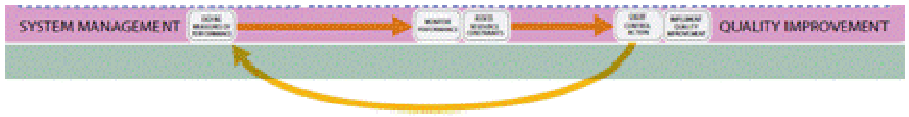
Figure 11: Develop and refine care model module



System management and quality improvement

The ninth and final module is a systems management module. Irrespective of how the activities in the other 8 modules are put in practice and organizationally embodied, the efficiency and effectiveness of the overall system has to be assessed.

Figure 12: System management and quality improvement module

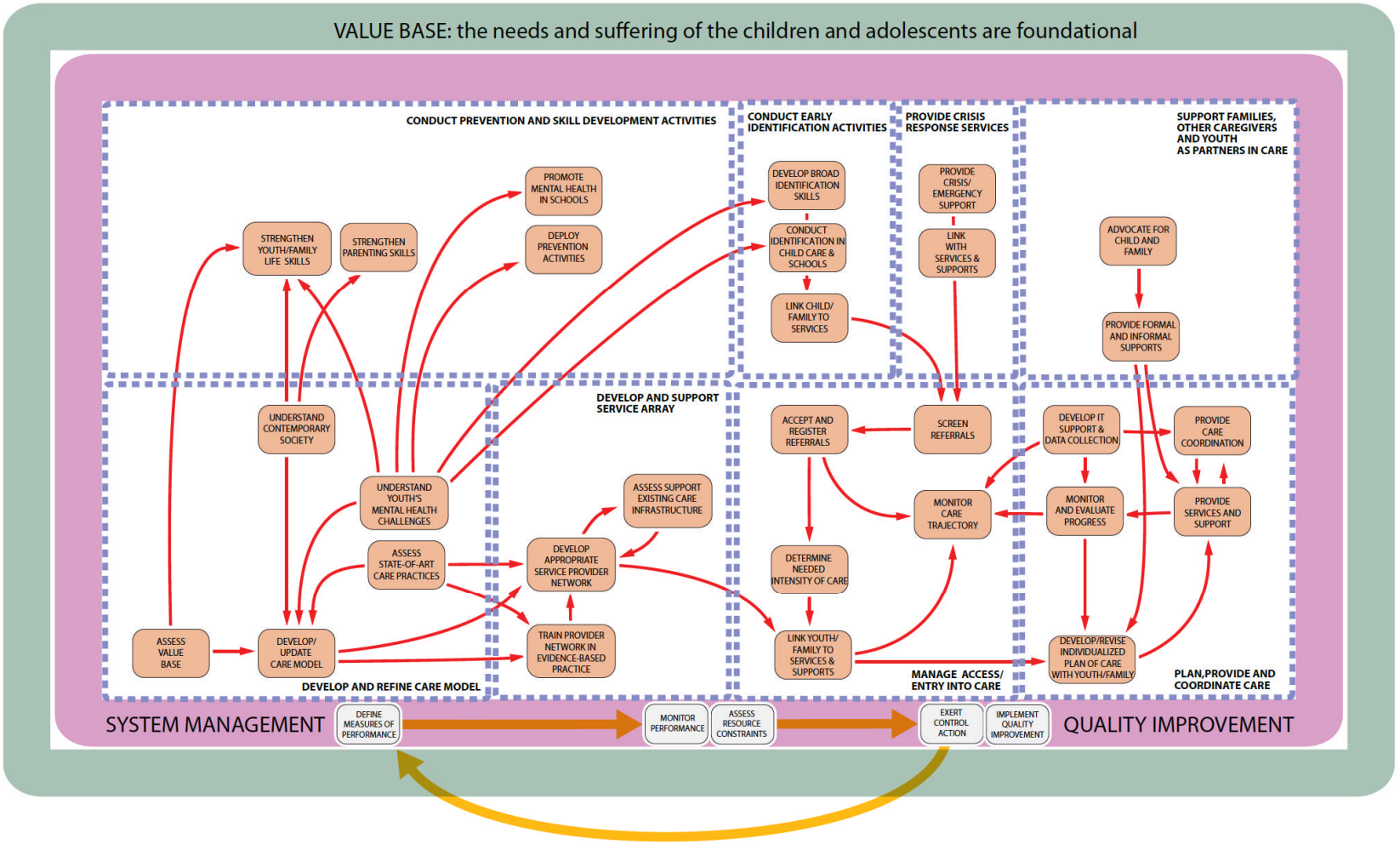


The module consists of 5 activities:

- Define measures of performance
- Measure performance
- Assess resource constraints
- Exert control action
- Implement quality improvement

Figure 13: Full activity model

(The French version of this Activity Model can be found in Appendix 7)



4.3.2. Discussion

It is important to consider the activity model for what it is and respect the logic it embodies. As pointed out in the introduction to the previous paragraph, the model should not be read as an organization chart, or as a process flowchart that shows how people (patients) move through a care system. In section 4.2.4 we have pointed out that the notional CAMHS system needs to support a transformation at three levels: a family/child level, a service level and a system level. At the family and child level the CAMHS system needs to assure that the suffering of the child is mitigated; at the services level it needs to support better co-ordination; at the policy level it has to ensure adaptiveness and fidelity to the value base.

The activity model is a vehicle to support these three basic transformations. The set of 35 interdependent activities, grouped into 9 functional modules, has to ensure that the system's purpose is realized.

The model is generic and it shares many features with conceptual models that have been proposed elsewhere. The National Council advice[13] proposes a mental health care system for children and adolescents that consists of 6 modules:

- A (semi-) residential care function;
- An outpatient service function;
- A prevention, detection and early intervention function;
- A crisis, emergency and assertive care function;
- A function that liaises with home and community-based (after) care services;
- A number of specialised care modules for specific target groups (addiction, young delinquents).

It is obvious that there is an overlap with the activity model suggested in this study. In both cases there are prevention, detection, and early intervention and crisis/emergency functions. Also the liaison function is explicitly present in both models. However, the perspective adopted by the two conceptual models is slightly different. Our activity model does not specify *where* care has to be provided. It simply indicates that, based on an assessment of the intensity of care needed, a care plan is put together, implemented and monitored. The National Council's advice[13] does refer explicitly to residential and outpatient facilities. However, the activity model needs to be considered in conjunction with the root definition, from which it takes its departure. The root definition stipulates that services will be delivered in the least restrictive environment possible and that to the extent possible priority will be given to home and community-based services. These requirements will determine the actual decisions taken at policy and service level about exactly what services and supports to offer in given circumstances.

So, on the one hand the activity model is **generic and allows for different approaches in operationalizing it**. This is a strength, as it can be readily adapted to different regional settings. The activity model can also be specified for specific target groups. For the very large group of young people with no or very mild mental health challenges the model's prevention and early detection modules will be most important. For youngsters with more complex problems the core 'plan, provide and coordinate care' module will be most important (with all the other activities supporting or enabling the activities taking place in the care provision module). The activity model is even able to **accommodate different balances between a population and a target group approach**. Depending on the relative weight of each in a nation's or region's policy, more resources can be allocated towards the prevention and skill development activities as compared to the screening and treatment activities.

The activity model, on the other hand, also reflects the specificity of the multisystems coordinated care model that is envisaged by this study. The family/youth support module is distinctive of a strength-based approach that wants to give families and young people a stronger voice in how mental care is provided. The 'develop and refine service array' draws attention to the need for continuous innovation in providing a broad service offering that goes beyond traditional inpatient and outpatient services. The co-ordination and information management activities in the 'plan, provide and coordinate care' module explicitly acknowledge the need for collaboration and information exchange within and beyond the mental health sector. The 'develop/refine individualized plan of care with youth/family' points towards 'assertive' approaches in delivering care. So as a whole the activity model reflects the distinctive features of a newly emerging care philosophy. As indicated before, the activity model should

not be dissociated from the root definition with which it is narrowly connected and which provides necessary framing.

The activity model will gain additional specificity when its activities are superimposed onto a stakeholder map. This is the subject of the next section in this report.

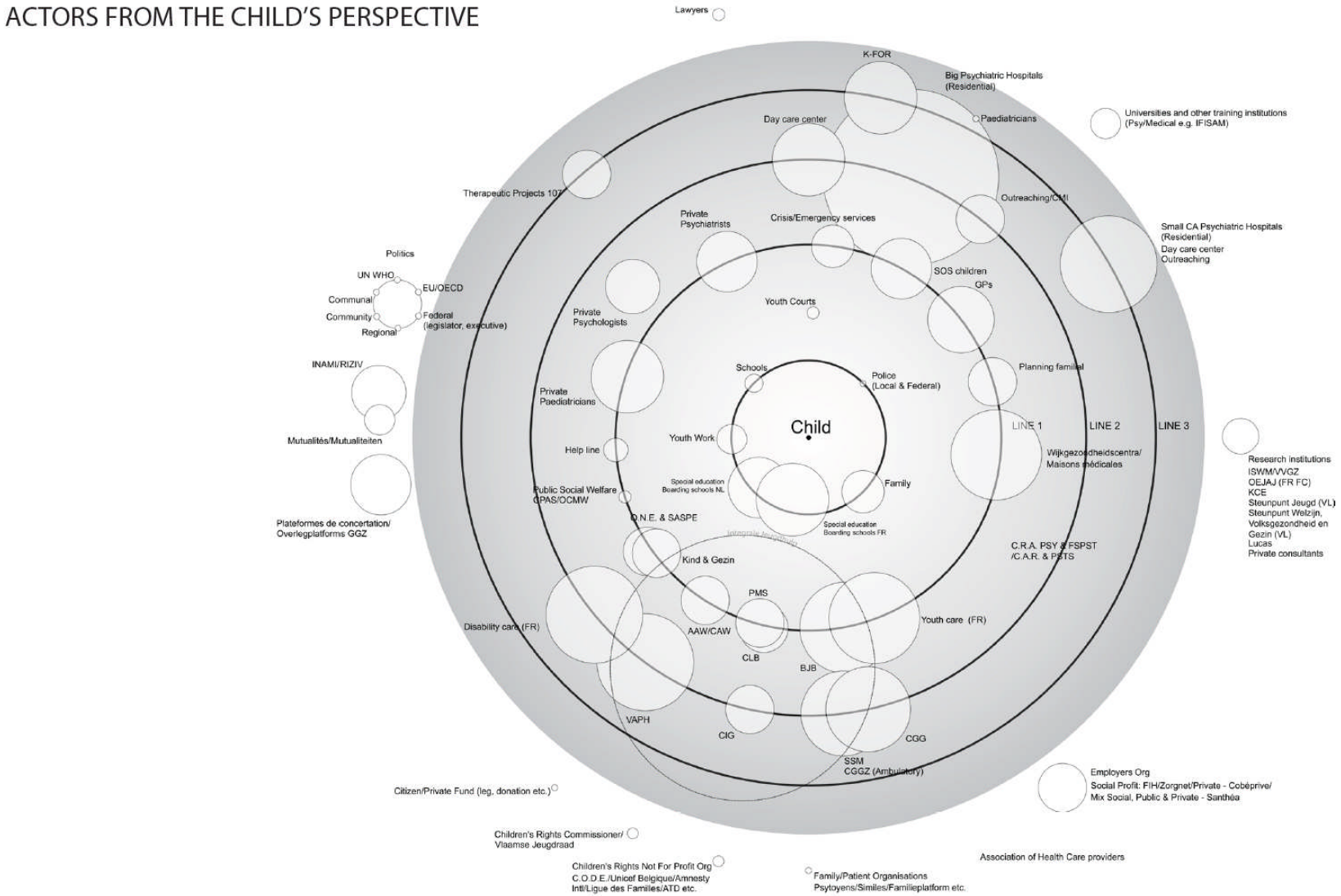
4.4. Stakeholder mapping

A third element in the sketch of a scenario of a more effective CAMHS system is a stakeholder mapping which takes the form of a visual representation of the care and support services and stakeholders arrayed around the child. So the stakeholder map takes the existing CAMHS system as a starting point.

4.4.1. The 9 stakeholder mapping diagrams

The visual logic of the basic diagram is quite straightforward.

Figure 14: Base diagram stakeholder mapping



The child is put in the center as the nodal point of the CAMHS system. Around the child, supports, services and stakeholders are arranged on a set of concentric circles. Each actor is represented as a bubble. Part I of this study provided the basis for an inventory of actors which was complemented by ad hoc suggestions from stakeholders.

- Closest to the child are the supports in his natural environment: family, school, youth work, police (also called the 0d line).
- On the next circle we find 1st line support and care services, including CLB/PMS in schools, GPs, community health centers, family support centers (ONE, Kind & Gezin), private paediatricians and psychiatrists, youth care organizations, help lines, crisis centers.
- The next circle out includes 2nd line, specialized care services: ambulatory mental health care (SSM/CGG), outpatient units in psychiatric hospitals, disability care, mobile/outreaching care teams.
- The next circle includes specialized 3d line services: residential facilities in small and big psychiatric hospitals, K-FOR units, and some of the therapeutic projects created under art. 107 of the Hospital Law that have a bearing on adolescent mental health care.
- The outer circle includes stakeholders that do not have support or care provision function but have an impact on the CAMHS systems as regulators (political bodies), medical insurance association (INAMI/RIZIV), health insurance funds ('mutualité', 'mutualiteit'), concertation platforms, advocacy organizations, employers organizations, research and educational institutes.

These service layers are grouped concentrically around the child but that does not mean that specialized services are physically and culturally far removed from the child. Also 3d line services, for instance, can be truly child-centric.

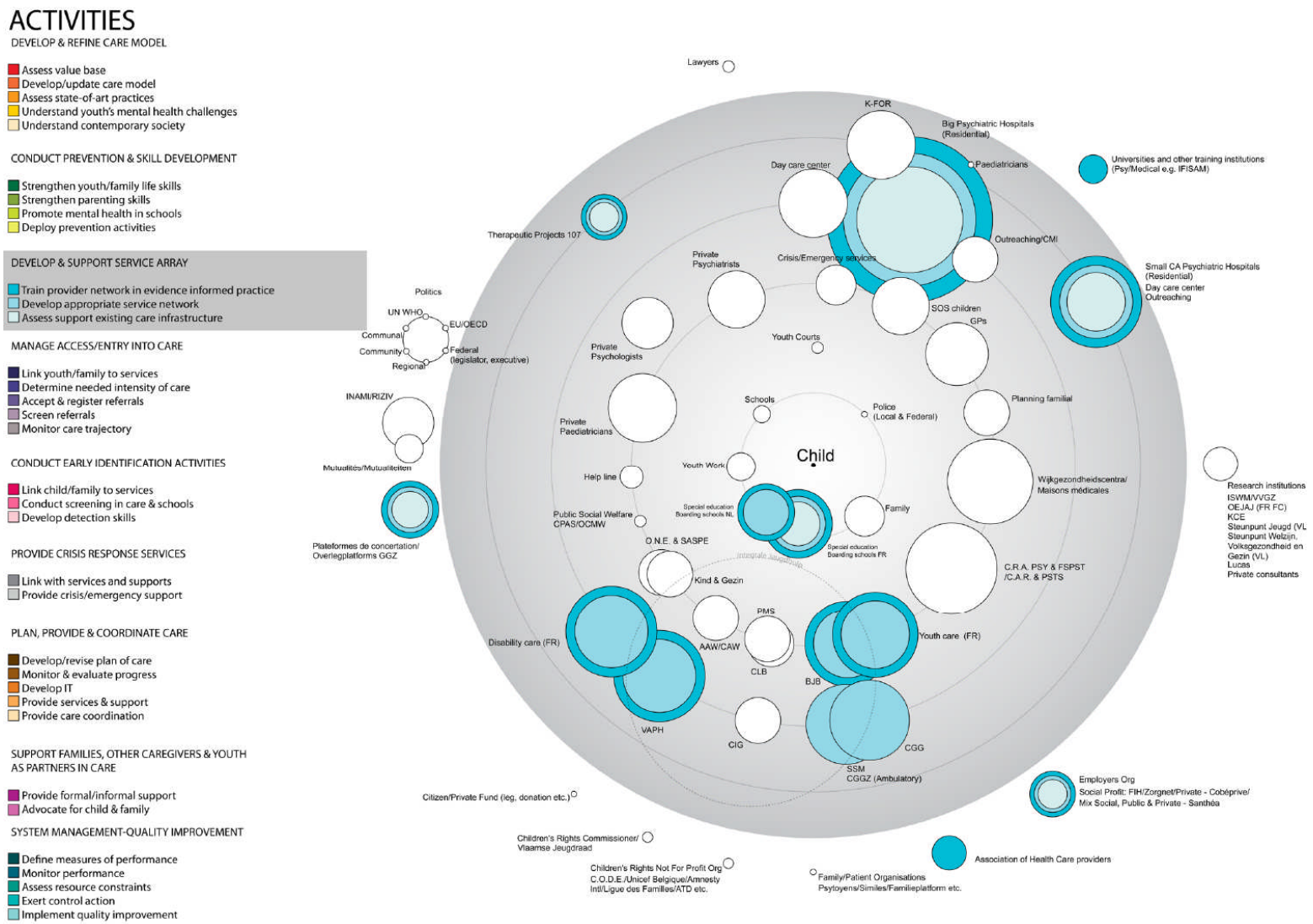
The reference to 'lines' has not been withheld in the diagrams as it is not an officially sanctioned terminology. Professionals, however, refer very often to it.

Note that actors that are similar have been grouped together. Actors that consist of distinctive functional subunits have been visualized as such. The diagram has been designed at a level of granularity that does not compromise readability. It is possible to develop an even more finely detailed diagram.

The stakeholder mapping is built up in layers on the base diagram. **A first set of layers connects to the 9 functional modules and the 34 constituent activities** of the activity model. There is one separate diagram for each module, visually coded by a distinctive color palette (reddish, greenish, brownish, and so on). Each activity is associated with one color shade of the palette. Activities are linked to the actors included in the stakeholder map. **The size of the actor bubbles is proportional to the number of activities they are cumulatively engaged in (not intended to be a reflection of importance)**.

As an example, the diagram is shown associated with the functional module 'develop and support service array' from the activity model. The color palette is based on shades of turquoise. The module includes three activities: 'assess support existing care infrastructure', 'develop appropriate service network', 'train provider network in evidence based practice'. An actor in the stakeholder map that is shown as three concentric circles with different shades of blue engages in all three activities. Psychiatric hospitals are an example. Universities, on the other hand, only engage in training and are represented a single dot. The same logic applies to the other functional modules, the number of activities of which varies between 2 and 5.

Figure 15: Stakeholder map with additional coding of activities



The full set of maps can be found in Appendix 8 and the Actor list in Appendix 9.

The stakeholder mapping has a tentative character. It is based on the research team's assessment, informed by a familiarity with the broader CAMHS system developed during this project. It has been validated by checking the published mandates and mission statements of organizations on the web and in printed references. But it has not been the subject of a detailed point-by-point assessment with knowledgeable representatives of those organizations. Stakeholders have been able to inspect these maps at the validation workshops and many explicitly said they liked them. Nevertheless there will undoubtedly be scope for improvement and refinement.

Furthermore, every reading would be a matter of debate as **the mapping assumes a hybrid character with an idealized layer put on top of the existing stakeholder landscape**. Indeed, the base diagram is a representation of the existing CAMHS system with known, identifiable actors. Connecting the activity model to it frames the mapping within the logic of that notional model (as it represents the set of activities needed to realize the purpose embodied in the root definition). Associating activities to actors will therefore always require a degree of interpretation. This is precisely the value added of this mapping. Rather than to represent an objective view of reality, it offers stakeholders an instrument to question and debate their own role in the CAMHS system.

A final provision concerns the fact that the stakeholder mapping with layered activities does not in any way give an indication of the amount of resources allocated to activities, how central they are to actors' mandate and how effective they are being performed. Again, this reinforces the positioning of these diagrams as a heuristic and positioning element.

Inspecting the 9 layered diagrams does transmit a few messages, however. First, meshing the 9 functional modules (and their constituent 34 activities) with the about 40 actors that populate the stakeholder landscape **clearly demonstrates the operational and regulatory complexity and multidimensionality of the CAMHS system**.

Further, the diagrams clearly demonstrate the **potential of many actors to contribute to the diverse activities that make the CAMHS system tick**. For example, almost all actors can and should be implicated in further developing and refining the care model (a functional module in the CAMHS system where strategic learning takes place). It is also clear from the maps that the access to the CAMHS system is much diversified ('manage access/entry into care'). System management and quality improvement, on the other hand is the privilege of particularly the actors on the outer circle.

4.4.2. Relationships between the different actors

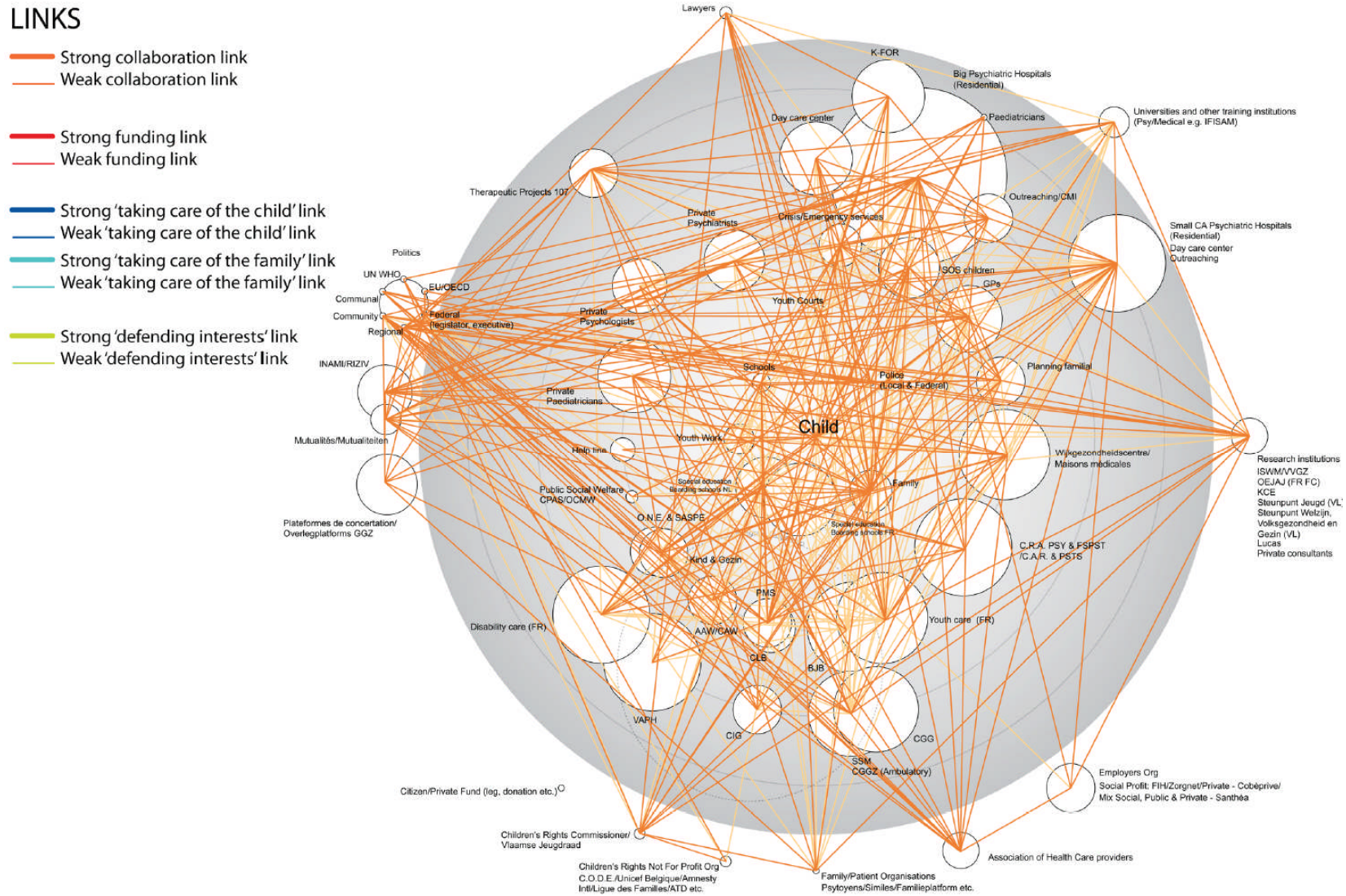
A second set of diagrams shows the relationships between the different actors. This again is a reflection of 'reality' as it can nowadays be observed. Four types of relationships have been distinguished:

- Collaboration;
- Funding;
- Taking care of;
- Defending interests of.

Each type of relationship is coded by another color. An orange line between two actors denotes a collaborative relationship. The 'taking care of' relationships all end up in either child or family. Funding relationships all start from the political or social security actors. A distinction is made between 'strong' and 'weak' relationships (as shown by the thickness of the line). The superimposition of the diagrams with the 4 types of relationships is a tantalizing visualization of the system's complexity.

Again, these assessments have been made based on the general familiarity with the system. The intention of this brief research trajectory is not to be totally accurate but to show a general anatomy of a complex system and to demonstrate the potential of this instrument to help stakeholders in positioning themselves in this system. Ultimately this tool could be further developed into an interactive portal to access an evolving evidence base on the actors populating CAMHS, their contributions to the system and the relationships tying them together.

Figure 16: Stakeholder map with added (collaboration) relationships



4.5. Insights from the validation workshop

The validation workshops were held on October 18 and October 20 for the Dutch-speaking and French-speaking groups respectively. A workshop report is included in Appendix 10.

Broadly the validation workshops confirmed the pertinence of the diagnostic analysis.

The solution elements that were extracted from the roundtables and interviews were not disputed but numerous questions as to how they should be operationalized were raised. An important question that came up in both language groups was how a more effectively collaborative CAMHS system could emerge without the pressure of unduly restrictive structures, guidelines and evaluation protocols.

The root definition was welcomed as a good and comprehensive statement of the CAMHS system's purpose. Suggestions were made to improve the wording of the definition. A key concern of both Dutch and French-speaking stakeholders was to nuance the position of the family in the CAMHS system. The mental suffering of the child ought to be the pivotal element; the family should not command an equally central role. Furthermore, it was advised to broaden the notion of immediate social environment beyond the family proper to anyone responsible for the child.

The activity model was found to be more difficult to internalize by the workshop participants. Its general scope and anatomy (9 functional modules) were endorsed. However, a number of misunderstandings as to its precise nature became evident during the discussions. In general there was a need to better outline the contributions of relevant subsectors and professional groups to the activity model. The logic underpinning the model was seen by some as too managerial or functionalistic.

These discussions certainly demonstrated the complexity of many of the issues surveyed in these validation workshops. There was a feeling that some of the questions warranted more time for discussion. Furthermore, the workshops were attended by a number of stakeholders who had not been involved in the process earlier on. Some of them were deemed quite influential and it seemed advisable to allow them to formulate their ideas more extensively. Hence, it was decided to follow up with a 'maturation phase' of about six weeks (stretching over the end of the year holiday period) which would be dedicated primarily to a second round of face-to-face interviews. During this period written feedback were also collected based on non consolidated summaries of each validation workshops (Appendix 11 and 12) and a short stay observation conducted (see section 2.2.2.1)

4.6. Insights from the consultation round interviews

Following up on the validation workshops it was decided to build in a maturation phase to allow stakeholders to digest the material that was proposed at the workshops, to give certain influential stakeholders a better opportunity to voice their opinions, to elucidate some of the controversial and difficult points that had come up in the validation workshop and to include a number of complementary perspectives, particularly from professionals in adjacent sectors.

Below key insights from the consultation round have been summarized. They have been divided into two groups. A first group adds diagnostic elements to the analysis that had been supported by the initial round of interviews and by the roundtable discussions. So these are elements of concern with respect to the current functioning of the CAMHS system. A second part collects proposals for improvement of the CAMHS system. These are, therefore, solution elements that come on top of what has been suggested in the interviews, roundtable discussions and validation workshops.

4.6.1. Summary of diagnostic elements

- The consultation round confirmed the diagnostic analysis discussed earlier in this report. The fragmentation and compartmentalization of CAMHS, enmeshed in a complex set of institutional, sectoral, cultural and professional drivers, was directly and obliquely confirmed as the foundational problem.
- The mental health care professional's ethical compass needs to deal with a lot of pressures around the nodal point of the suffering child: motives of personal gain, the increasingly economic logic undergirding health care systems, power struggles, the increasing juridization of CAMHS. Outsiders perceive professionals not to be always wholly successful in navigating these choices.
- The role of the family needs to be nuanced according to child psychiatrists. The dogma of family-centered or family-driven approaches is seen as unhelpful. They are in favor of a case by case approach.
- A point that is raised again and again is the very fluid context in which mental health professionals have to do their work because of the developmental dynamic of children, the potential heterogeneity of their 'milieu de vie', the increasingly fragmented and challenging nature of family life and the wide range of therapeutic approaches available. As a result therapeutic flexibility is considered vital.
- Interviewees drew attention to several groups of 'forgotten' children that are not easily accommodated by CAMHS, particularly those suffering from double diagnosis (mental retardation and psychiatric problems), violent behavior, very young children (0-6 yrs), young adults suffering from autism that need long residential treatment, young delinquents from immigrant descent.
- CLB/PMS confirm their potentially important place as access gate to CAMHS. But they are bound by a mandate that restricts their focus to the educational dimension. These services also lack the staff to go beyond that mandate. CLB/PMS fulfill a very active role as interface between various youth care organizations. But links with specialized services are sparse and formalized. Child psychiatrists are assumed to have little interest in partnering with these school-based services.
- GPs have a negative, even cynical perception of the willingness of child psychiatrists to support and liaise with them ("we are 'Fremdkörper', 'quantité negligable'"). GPs lack information, contact points, training and coaching. Vice versa child psychiatrists have been observed to comment very little on the role GPs might play in a more efficient access to CAMHS.
- Institutional, cultural and professional barriers impede the collaboration between youth care (governed by federated authorities) and specialized services (governed by federal government).
- The perspective of child psychiatrists on ambulatory services (CGG/SSM) is colored negatively. There is a quasi-consensus that these services work inefficiently, lack transparency and liaise unsatisfactorily with specialized services. They are seen as resistant to change.
- As regards crisis and emergency care, no new elements were suggested. The lack in facilities was confirmed. Outreach projects are viewed positively but lack critical mass.
- Some professionals agree that CAMHS, compared to adult mental health, has always been underfunded. Increased networking, coordination and outreaching work will require more financial resources. But as will appear from the solution elements suggested, there are many interviewees also who think that it is not necessarily a matter of getting more resources. Reallocating, pooling and braiding funds from different services involved in youth care and mental health services is expected to create new possibilities to finance the reform of CAMHS.
- As regards evaluation it is quite clear that child psychiatrists are resistant to formalized approaches that increase administrative burden, do not match the value base underpinning their practice and have little or no therapeutic relevance.

4.6.2. Summary of solution elements

The solution elements suggested in the consultation rounds are fairly scattered. Nobody claims to have 'the' solution in the pocket. The key elements can be summarized as follows:

- First line professionals (schools, family support, social care, GPs) see a lot of potential to improve prevention identification and liaison with specialized services. Arguably most of these services are governed by the federated authorities and as a rule have a weak interface with the federally funded psychiatric hospitals and ambulatory centers. These institutional barriers need to be negotiated. In addition, child psychiatrists need to be persuaded to support these services. Finally, the level of mental health care related expertise in these services needs to be upgraded.
- To bolster crisis and emergency services a mix of mobile teams and a geographically distributed network of fixed units is advocated.
- Professionals seem to advocate a pragmatic, bottom-up approach in moving ahead with reform, preferably driven by appropriate, goal-directed incentives and enabling conditions (shared professional secrecy). It is important that actors are granted a lot of flexibility in shaping these bottom-up solutions. There is little trust in setting up and formalizing new structures. The suggestion is to work with what is already there. But a clear political signal is expected to set the process in motion.
- Many interviewees seem to agree that the reform could be funded by pooling and braiding of funds from different services involved in psychosocial and mental health needs of children.

5. GAP ANALYSIS AND RECOMMENDATIONS

At this point this study has resulted in a diagnostic analysis that synthesizes key problems in the existing CAMHS system. In addition it has, with stakeholders, co-developed and validated a root definition that delineates the purpose of an envisaged mental health system for children and adolescents.

"The CAMHS system is an array of ethically guided, professionally supported and evidence-based services for children and adolescents with, or at risk of, mental health challenges and their entourage, that are provided in a co-ordinated, personalized, developmentally appropriate, and culturally competent manner in the least restrictive environment that is clinically appropriate and most adapted to the child's needs, to help these young people to achieve better wellbeing and fulfillment, at home, in school, in the community and throughout life."

That root definition has been the basis for the development of an activity model that brings together the activities needed to realize the system's purpose. A stakeholder mapping has subsequently given a tentative outline of the contributions of and relationships between different actors. Activity model and stakeholder mapping are not definitive ground plans of a future CAMHS system. They merely lay down the contours of a future system that needs to be given substance by carefully designed interventions in the existing system. The question is then which interventions need to be prioritized in making a transition towards a future system that is able to realize that future purpose as encapsulated by the root definition and the activity model.

The ambition of the transition is first, to improve the wellbeing of children and their families (or any other party that is responsible for the child), particularly those that currently are (or are at risk of) experiencing poor support and care by mental health services. **This child and family-level transformation** is complemented by a **service-level transformation** that seeks to increase the level of coordination and efficiency of mental health services and supports. Finally, the envisaged CAMHS system is evidence-

based, resilient and capable of dealing with the evolving requirements and needs of children and families in contemporary society. This is a third and **system-level transformation** that is supported by the proposed recommendations.

In this section, key bottlenecks in the CAMHS system and important solution elements are quickly reiterated as a basis for a set of recommendations for interventions. These recommendations have been submitted to stakeholders' scrutiny in a final consolidation workshop.

5.1. Recapitulation of key problems facing the existing CAMHS

Diagnostic elements have been harvested from the roundtable discussions (section 3.1.), the exploratory round of interviews (section 3.2.), validation workshops (section 4.5) and from the consultation round interviews following the latter (section 4.6). In addition key policy documents and research studies have been consulted. The key system deficiencies can be summarized as follows:

- The Belgian mental health care system for children and adolescents is **fragmented and compartmentalized**. This leads to suboptimal care and to waste and efficiencies as revealed by the long waiting lists for patients to access the system. The fragmented system is increasingly put under pressure as demands for mental health care from children increase and become more complex.
- In response to these pressures there is a significant **dynamic of innovation and experimentation** in the system. But these remain localized initiatives that quickly saturate and are not able to build critical mass. The capacity of the system as a whole to adapt to changing requirements is limited.
- There is **no clear overarching vision**, and no explicit shared goals and ethical guidelines for the CAMHS system. The fundamental right of all children and families to effective services and supports and to drive their own care has seldom been mentioned as a cornerstone of a health care system.
- **Access to the CAMHS system is diffuse and unstructured**. The effectiveness of frontline (0d and 1st line services such as school-based counseling, youth care, GPs, community health centers) in liaising with specialized services is hampered by institutional and sectoral fragmentation and by lack of mental health competences in non-specialized supports and services.
- The CAMHS system **lacks diversity in the supply of services** for young persons and their families, and is largely limited to traditional ambulatory and residential services. Ambulatory services are seen to be underpowered and inefficient. There is a lack of emergency and crisis facilities and of mobile 'assertive care'. In general the system lacks home and community-based treatment modalities and supports that are sufficiently intensive to provide alternatives to treatment in inpatient and residential settings.
- There are **groups of 'forgotten' children** that are not easily accommodated by CAMHS, particularly those suffering from double diagnosis (mental retardation and psychiatric problems), violent behavior, very young children (0-6 yrs), young adults suffering from autism that need long residential treatment, young delinquents from immigrant descent.
- There is **no assessment of the overall effectiveness of the CAMHS system**. Evaluation methods are either non-existent or inappropriate, adding to the administrative burden of practitioners and constraining the ability for data-informed decision making and continuous quality improvement at both the system and service levels.

5.2. Recapitulation of key solution elements

Key solution elements have come to the fore in this study through stakeholder input (section 4.1.1 and 4.1.2), and input from literature (section 4.1.3, 4.1.4 and 4.1.5) approach. They are the following:

- Development of **cross-sectoral care networks**: there is a need to better connect ambulatory, residential, home and community-based mental health services, and improve liaison and consultation across youth sectors;
- **Strengthening of the crisis/emergency capacity**: there is a clear demand for an expanded crisis/emergency capacity connec;
- **Broadening of the service array**: to include home and community-based formal and informal supports for children and families;

- Developing **clear accountabilities and solutions for children suffering from complex problems and/or violent behavior**: an end has to be put to the practice of 'passing the buck around', meaning that service providers try to avoid complex cases by forwarding these people to other services;
- **Strengthening of prevention, identification and early interventions**;
- **Strengthening of capabilities at the CAMHS system's entry gate**;
- Articulating **vision, goals and value base**.

5.3. Bridging the gap to a more effective, co-ordinated and ethically guided delivery of care

Nine recommendations have been proposed to bridge the gap between the current, fragmented and siloed, CAMHS system to an effective, co-ordinated and ethically guided delivery of supports and care that crosses sectorial and program boundaries. They are:

- Recommendation 1: To strengthen the capacity to provide accessible, responsive and effective crisis and emergency care to children and adolescents;
- Recommendation 2: To deepen and support the professional competences in non-specialized mental health care so as to improve the quality of assessment, care and eventual liaison with specialized services;
- Recommendation 3: To expand mental health-oriented prevention, identification, intervention and promotion for infants and toddlers particularly in vulnerable and deprived populations;
- Recommendation 4: To expand formal and informal support services for both children/adolescents and families;
- Recommendation 5: To strengthen accountability and expand and reinforce capacity to provide flexible and assertive care in the natural environment of children with serious, multiple and complex mental health problems;
- Recommendation 6: To improve cultural and linguistic competences of children and adolescent mental health care providers and youth workers so as to accommodate the cultural specificities of the populations they serve;
- Recommendation 7a: To establish a respectful, multilateral dialogue on a shared vision for the broader child and adolescent mental health services system including all relevant stakeholders (including representatives of children and families);
- Recommendation 7b: To develop an ethical charter to guide caregivers in formulating answers to the suffering of the child;
- Recommendation 7c: To maintain and strengthen cross-sectoral forums at different institutional levels that activate and mobilize collaboration and network formation on an ongoing basis;
- Recommendation 8: To improve a qualitative and quantitative understanding of the need for and offering of services for children and adolescent mental health care, to effectively leverage regionally distributed care facilities and to facilitate the formation of regional care networks;
- Recommendation 9: To apply and develop evaluation methods based on international best practices, reflecting national or regional specificities and in harmony with ethical guidelines, with the aim to reinforce accountability, professionalism, quality improvement and multidisciplinarity in providing mental health care to children and adolescents.

Hence, the recommendations cover three broad substantive areas:

- Recommendations 1 to 4 collectively want **to marshal the demands made on scarce and expensive specialized mental health services** for children and adolescents. The aim is to ensure that young people receive appropriate care in the least restrictive and most adapted environment. This is expected to lead to a more prudent use of specialized care and residential facilities (note that it is not assumed that the level of specialization is strictly correlated to the location where the care is provided). The recommendations want to achieve this via prevention, empowerment of users and their entourage (families), adequate filtering at first line care services and by

strengthening the system's capacity to deal with mental health-related crises.

- Recommendations 5 to 6 focus on **strengthening the practice approach of mental health professionals, particularly as regards caring for children who suffer from serious, complex and multiple mental health problems**. These complex situations may or may not be compounded by violent behavior or cultural barriers. The proposed recommendations want to plug gaps in accountability in dealing with these young people, reinforce a flexible and assertive approach to providing care for theses children in their natural environment and improve the cultural competences of care providers.
- Recommendations 7 to 9 are targeted towards **strengthening the adaptive capacity of and the ethical guidance within the future CAMHS system**. They seek to do this by making sure that actors in the system, including representatives of children and families (entourage), engage in cross-sectoral forums to stimulate partnerships on an ongoing basis. It is proposed that all stakeholders commit to developing a shared vision and an ethical charter for the broader child and adolescent mental health services system. It is also recommended that continuous efforts are done to better understand the needs for mental health services and the regionally available service offerings. Finally, there is the suggestion to expand the application of appropriate evaluation methods to reinforce professionalism, quality improvement and multidisciplinarity.

Another way of understanding the recommendations is to see them as addressing three broad areas of 'prevention', 'intervention' and 'research and evaluation', which is congruent with CAMHS frameworks adopted in other countries, notably the Evergreen[15] in Canada (which includes a fourth component, here absent, namely 'promotion').

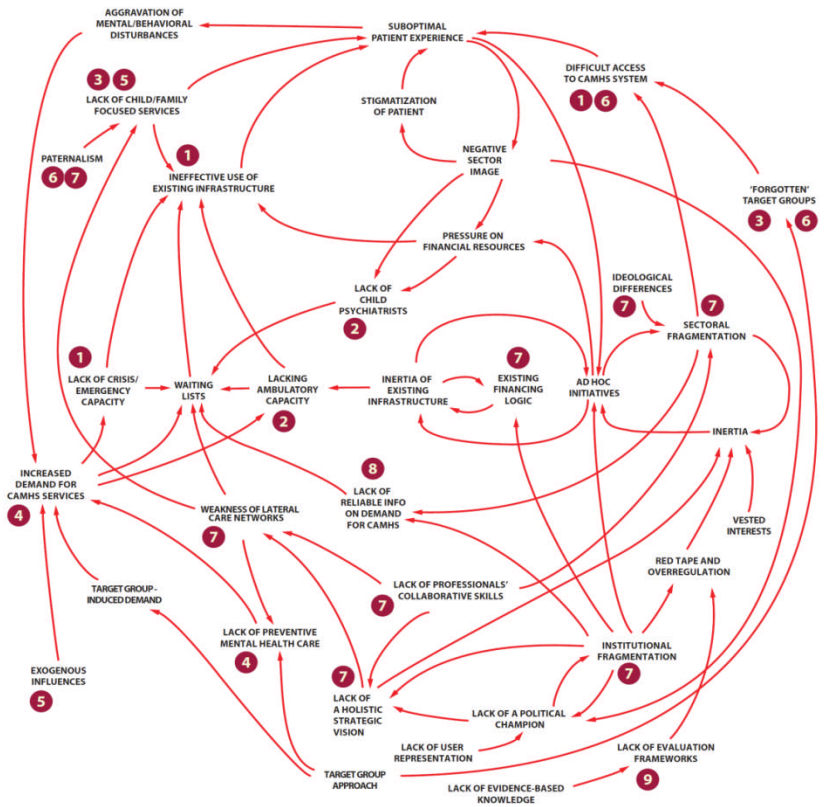
It is in this context also interesting to return to the diagnostic 'rich picture' and to verify how the recommendations map on the factors that populate the diagram. For example, it can be expected that the first recommendation – strengthening the provision of crisis/emergency care – will address the factors 'lack of crisis/emergency capacity' and 'difficult access to CAMHS system'. Table 7 provides an overview of these connections.

Figure 17 shows how the recommendations map onto the rich picture itself (with numbers referring to the associated recommendation). Clearly, many of the diagnostic elements are being addressed. This is an additional, informal validation of the scope of the totality of recommendations.

Table 7: Impact of recommendations on Rich Picture factors

Recommendation	Rich Picture factors
Recommendation 1: crisis/emergency care	Lack of crisis/emergency capacity Difficult access to CAMHS system
Recommendation 2: deepen non-specialist competences	Lack of child psychiatrists (indirectly) Lack of ambulatory capacity
Recommendation 3: prevention infants and toddlers	'Forgotten' target groups Lack of child/family focused services
Recommendation 4: expand formal/informal support services	Lack of preventive mental health care Increased demand for CAMHS services
Recommendation 5: flexible and assertive care for children w. complex troubles	Lack of child/family focused services Exogenous influences (family/individual resilience)
Recommendation 6: cultural and linguistic competences	Difficult access to CAMHS system 'Forgotten' target groups Paternalism
Recommendation 7: vision, ethical charter and cross-sectoral forums	Sectoral fragmentation Institutional fragmentation Ideological differences Lack of professionals' collaborative skills Lack of a holistic strategic vision Weakness of lateral care networks Existing financial logic
Recommendation 8: understanding of needs and service offering	Lack of reliable info on demand for CAMHS
Recommendation 9: evaluation methods	Lack of evaluation frameworks

Figure 17: Mapping of recommendations on rich picture



A draft version of these recommendations was submitted to stakeholders in a consolidation workshop, the final participatory event in the framework of this project held on 16 and 17 January 2012 for the French-speaking and Dutch-speaking groups, respectively. The report that summarizes the detailed response of the stakeholders can be found in Appendix 13. The intermediary reports sent as feedback to the participants of each linguistic group can be found in Appendix 14 and 15. Please note that 10 draft recommendations have been discussed by participants of which 2 have been merged to result in a total set of 9 recommendations. Also the sequence has been changed to reflect the substantive grouping highlighted above.

Here only the key insights from the workshops are included.

5.4. Insights from consolidation workshops

- The proposed recommendations were on the whole received as relevant and in accordance with the scope of reform of CAMHS that stakeholders were anticipating. None of the recommendations have been outright dismissed. Neither have there been proposals to expand the set with recommendations that address very different issues. This is an important observation.
- The workshop resulted in a significant number of suggestions to improve the recommendations in their substance and wording, which is already reflected in the version included in this section.
- Not all recommendations were perceived to be equally important. Although a consensual ranking was not achieved during the workshop, comments were made that reveal where the center of gravity for reform lies for the participating stakeholders. The two language groups partly converge on that matter. But there are differences between the two groups too.
- Recommendations nrs. 1, 2 and 3 are seen to be cornerstones of CAMHS reform for both language groups. These relate to the strengthening of crisis capacity, the reinforcement of first line mental health care capacities, and prevention targeted at young children, respectively. This seems to confirm that the CAMHS' main concern is to manage the inflow to specialized services and hence to make sure that its medical professionals are able to do the work (s)he are supposed to do, namely to provide specialized mental health care to those children most in need of those services.
- Recommendations nrs. 5 has also been affirmed as important by both language groups. There is agreement on the need for a more inclusive approach to mental health care, particularly as regards youngster struggling with complex problems, rather than the creation of new labels for very specific target groups. The strengthening of mobile, flexible and multidisciplinary teams to work with these children is seen

as a priority. In putting this into practice, however, the regional dimension plays a more important role in the French-speaking part of the country.

- Furthermore, the CAMHS sector acknowledges the need to continue a dialogue on an overarching vision and ethical guidelines for all professionals who are working with children coping with psychosocial challenges and mental health problems (Recommendation 7a and 7c). French-speaking stakeholders see an ethical charter as another key point (more so than their Dutch-speaking colleagues) as it may provide a counterweight to the excessive importance of an 'evidence based' practice (Recommendation 8b).
- There is also agreement between Dutch- and French-speaking stakeholders on the relatively low urgency of strengthening cultural competences of care providers (Recommendation 6).
- Groups had also mixed opinions on Recommendations nrs. 4, 8 and 9. These reflections have been reflected in the adapted wording and discussion of the recommendations in the following session.

5.5. Recommendations

5.5.1. Recommendation 1

To strengthen the capacity to provide accessible, responsive and effective crisis and emergency care to children and adolescents.

The lack of emergency and crisis capacity has been a prominent theme throughout this research study. It has been flagged, by some professionals, as the single most conspicuous and acute bottleneck in the CAMHS system (section 3.2.3.). The negative implications of this lack are widely felt: it aggravates the mental health difficulties for children and families, leads to frustration and discouragement of care providers (specialized care providers feel they are the 'rubbish bin' of the system) and gives rise to inappropriate use of existing facilities, particularly in specialized and residential care.

Stakeholders pointed out that the situation is particularly severe in Brussels where there are no facilities at all that cater for crisis and emergency cases.

Stakeholders observe that nowadays crisis care seems to be 'owned' by specialized mental health care services. There is a strong call for all parties working with children with mental health problems - including basic youth care and disability care - to take responsibility in providing an adequate response to acute and urgent situations. Short-term safety and security facilities can be made available outside of traditional hospital sites.

Remediating the lack of crisis and emergency capacity is subject of a previous KCE-study[10] and is also a key recommendation in the advice formulated by the National Council for Hospital Facilities.[13] The KCE-study illustrated that there is a clear trend in the literature for complementary models of intensive psychiatric care provision, including outreach services, crisis intervention team and age-appropriate day patient and inpatient provision. The KCE recommended to conceptualise emergency psychiatric care as a separate "function", rather than as a specific service/department with a priority on non-residential care.[10] The advice of the National Council for Hospital Facilities[13] proposes to work towards an integrated response to urgent or acute mental health-related situations through three distinct care functions: emergency care, crisis care and assertive care. Emergency care is usually linked to medical (somatic) complications and requires immediate intervention. Mental health-related crises allow for a response time of a few days. Assertive care is a mobile, tenacious and adaptive process of engagement in the natural environment of people who are most disengaged from society and services and hence otherwise difficult to reach. In this recommendation the focus is on emergency and crisis interventions.

Additional crisis care capacity could be operationalized in different, non-mutually exclusive ways: 1) via a fixed fraction of the (K-) beds available in psychiatric hospitals reserved for crisis admissions (a measure to be activated by a federal injunction), 2) via autonomous and local units that are not necessarily attached to a hospital (but to a local day care centre), and 3) via interconnected, mobile, multidisciplinary and cross-sectoral teams operating at a regional or 'care basin' scale to support non-specialized mental health services. These mobile units could also engage in short trajectories of assertive care when asked for. These stakeholder suggestions are broadly in line with the National Council advice. A cross-sectorally staffed contact point for users would have to be established to ensure crisis response at all times (24/24h; 7d7d with the injunction to

refuse children and adolescents without an appropriate assessment of the situation).[10]

There are, therefore, two key principles underpinning a more effective crisis and emergency capacity: the service has to be embedded in a cross-sectoral network of care providers, and it has to be flexible as to where it is offered, preferably in the least restrictive environment possible.

Networks ought to be self-organizing, incentivized by rewards for offering adequate coverage, availability and quality of care. All partners involved have to allocate appropriate resources and develop competences to support crisis care so that they can take quickly responsibility, particularly as regards youngsters that have been in treated by their own services. Additional resources from the federal government would be needed to finance the 'crisis beds' that fall outside the hospital's default K-bed contingent.

5.5.2. Recommendation 2

To deepen and support the professional competences in non-specialized mental health care so as to improve the quality of assessment, care and eventual liaison with specialized services.

One of main concerns that has been persistently voiced by providers of specialized mental health care is the haphazard way in which children end up in specialized, residential care facilities. The quality of the filtering of children and families seeking support with mental health problems to progressively more specialized services suffers from the persistent fragmentation of CAMHS. As indicated under Recommendations 1 and 5, the deficiencies of the system manifest themselves very clearly when it comes to dealing with acute cases of crisis and emergency and with youngsters suffering from multiple, complex mental health problems. But also in less extreme cases care trajectories risk being tortuous and disjointed, obviously leading to additional suffering for the child and family.

Matching the level of clinical expertise at the point of system entry to the complexity of the case is increasingly seen as good practice in mental health care. The Choice and Partnership (CAPA) method - an innovative but still unvalidated approach that has been introduced in a number of Belgian psychiatric hospitals - embodies this principle[q].[9] However, many children enter the system via other routes, be it school, GP, youth care or daycare centers. It is not possible to have specialized expertise available at all these entry gates. Stakeholders in this process have voiced little support for the idea of a 'single access point', supported by the fact that it doesn't work well in countries that have introduced it.[9] Instead, they argue for a strengthening of basic skills in non-specialized care and counseling services – PMS/CLB, GP, youth and social care - and the possibility to bring in specialized capabilities on a consultative basis as and when necessary. The development of training packages and standards (e.g. primary care physician training program for identification; diagnosis and treatment of the most common child and adolescent mental disorders) by the British Columbia Medical Association, is a specific example from abroad with the purpose to contribute to this goal.[9]

This recommendation is also included in the National Council's CAMHS advice.[13] Part I of this study points out similar good practices in other countries: for example, in the UK inter-sector standards have been set out in knowledge, competencies and 'common core' skills in the field of child and adolescent mental health for all staff working with this age group. Furthermore, modalities for intra-sector collaboration have been developed to allow specialized CAMHS professionals to advice and support CAMHS staff of less specialized tiers.[9]

Stakeholders point towards the strained relationships between these first (or zero) line services and the clinical experts, partly because of procedural and deontological factors, partly because of unhappy past experiences. Hence it is all the more important that transversal forums are created in which partners can seek alignment (see Recommendation 7).

Bolstering mental health-related skills should enable services to better identify potential problems, and to intervene within their own remit, particularly when it comes to assess and stimulate children in their own developmental and contextual setting. It should also improve the ability to liaise with other actors, when necessary. This presupposes a sufficient grasp of legal frameworks that are operative in CAMHS.

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[q] http://www.capa.co.uk/

The implementation of this recommendation needs to happen with respect for all kinds of professionalism brought to bear in CAMHS. Stakeholders are of the opinion that curricula for GPs and other generalist care providers could be bolstered when it comes to children and adolescent mental health problems. However, the intention ought not to be to turn everyone into a mental health care specialist. Also children and their direct social environment need to be recognized as valuable sources of expertise by specialist and non-specialist care providers.

A key role should be allocated to general practitioners. According to some authors, GPs refer around 10% of their contacts onwards, irrespective of the care system in which they are working. This means, according to these authors, that they are able to handle 9 out of 10 cases, including psycho-social and mental health complaints, themselves.[16] However, an evaluation of the Belgian "therapeutic projects" learned that integrating the primary care sector in CAMHS services was problematic.[11] The difficult relationship between the GP and mental health services was confirmed during stakeholder contacts in the current study. GPs complain about lack of recognition, case-based support, training, and financial compensation for long consultations. Mental health professionals are seen to hide behind professional secrecy and inhibiting structures. Relatively straightforward measures such as remote coaching (via phone or web) by psychiatrists could make a significant difference. There is also a demand to receive targeted training to bolster identification and treatment skills. Family health care teams instead of solo GP practices are another approach to enhance first line effectiveness in dealing with young peoples' mental health problems (see also Recommendation 3).

Professionals who are interfacing between different lines or sectors ought to be supported by appropriate training (and even qualifications) as network mediators in CAMHS.

5.5.3. Recommendation 3

To expand mental health-oriented prevention, identification, intervention and promotion for infants and toddlers particularly in vulnerable and deprived populations.

Stakeholders consulted in this participatory research project are convinced of the dividends of investing in primary and secondary prevention, detection and early intervention particularly targeted to very young children and the unborn.

This is in agreement with the insights from the international review of CAMHS systems[13] where, across countries, there has been a move in recent years to allocate more resources to prevention of mental disorders.[9]

Also the advice of the National Council for Hospital Facilities[13] stresses the need for prevention and early detection and includes it as one of the four basic responsibilities of a CAMHS system. The advice recommends consolidating valuable and innovative initiatives, particularly those that target the parent-child nexus.

Stakeholders have motivated the stress on the early years (prenatal to age 5) by pointing to the UK Strategic review of health inequalities[18] which sees increasing expenditure on prevention early in the developmental life cycle as a key policy lever to reduce health inequalities later in life.

Stakeholders stressed that prevention efforts ought to be oriented in the first place towards disadvantaged and vulnerable groups ('selective prevention'[9, 19]). Risk sensitivity is a dynamic concept and potentially the consequence of many factors, including social, economic, cultural, educational, residential and family factors.[17] With those provisos in mind, stakeholders have referred to the following at risk groups: children from teenage parents, from parents with mental health problems and disabilities, children who have experienced trauma (e.g. suicide or violent death of parent), or have been exposed to physical or mental abuse, children with developmental retardation, or very young children who suffer from anorexia.

In addition stakeholders recommend to expand prevention activities beyond vulnerable groups to include all young people ('universal prevention') in the framework of the strengthening of a public health approach (as opposed to a 'target group' approach) that sees the

improvement of the psychosocial skills of all children (those with and without mental health problems) as a key goal of the CAMHS system. They pointed out the need for a balance between serving young persons with diagnosable disorders and this broader 'public health approach' that also includes strategies for mental health promotion and prevention. Also Part I of this study has found that mental health services, including programs of prevention and resilience building delivered within school contexts have proven to be effective.[9]

Mental health prevention falls under the remit of the federated authorities. Particularly first line care providers - including GPs, community health centers, family support organisations (Kind & Gezin, ONE) and school-based counseling services (CLB/PMS) - are instrumental in deploying prevention activities and application of indicated interventions. Their children and adolescent mental health literacy and capabilities need to be strengthened (see Recommendation 2). Particularly in the case of very young children, some stakeholders argue for a more assertive and outreaching approach to family support and school counseling. Places like the Maison Vertes[r] and the emerging 'Huis van het Kind' (Kind & Gezin) offer accessible places to infuse specialized mental health expertise in prevention activities.[9] Hence, partnerships with nurseries are recommended.

Stakeholders have also pointed out potentially unwanted consequences of early detection such as diagnostic lock-in and stigmatization.

5.5.4. Recommendation 4

To expand formal and informal support services for both children/adolescents and families.

Stakeholders have argued for a broadening of the mental health service array for children and adolescents. Today, with the emphasis on residential facilities and, to a lesser extent, on outpatient services, there are important gaps in the service offering, particularly in the area of home and community-based services. The latter include both outpatient services staffed by medical professionals as more informal supports delivered by paraprofessionals and peers.

An expansion of support services reinforces two important developments in mental health care. First, it ties into the increasing interest in a public health approach to mental health that encompasses prevention, identification, early intervention and promotion (see Recommendation 3). Second, it contributes to a more community-based model of care that fits with the dominant trend of providing care in the least restrictive environment (with reintegration into society via school or employment being a key complementary strategy). Formal and informal support services are also a key element in a System of Care approach.[14]

Support services for children and families (or children's entourage) can take many forms. A non-exhaustive list includes[14, 20]:

- mental health consultations;
- youth and family education;
- therapeutic recreation;
- therapeutic mentoring;
- after school services (for parents and children);
- integration and socialization activities (e.g. in sport and youth clubs);
- respite services (for parents and other caregivers);
- peer youth support;
- peer family support;
- support services to facilitate the transition to adult life.

Services are offered in people's natural environment - home, school, recreational spaces - or in community health centers. Proximity is key. This is primarily the remit of basic youth care and family support organizations (financed by federated entities). The principle of reinforcing mental health capabilities in the home, schools and first line services connects therefore to Recommendation 2 (and further on to Recommendation 7 as regional, cross-sectoral forums can offer the environment to design and incubate these kinds of services).

In addition to mental health, youth care and educational professionals from government-sponsored care providers, also privately operating professionals could be admitted to the provider network. Patient organizations and natural helpers can contribute by concrete assistance, emotional support and skill building. Stakeholders were of the opinion that

[r] http://www.lesmaisonsvertes.be/

adequate qualification and an allegiance with the ethical guidelines governing CAMHS (see Recommendation 7) are minimum requirements for admission to the network. As in all heterogeneous provider networks there is a tradeoff between the inclusiveness of the network and the ability to control the quality of the services delivered.

Although the critical role of support services is often cited in literature[21], most of these approaches belong to the realm of practice-informed interventions. An evidence-based parenting program that has been deployed in Belgium (by one of the stakeholders involved in this research process) is Triple P (Positive Parenting Program), a parenting and family support strategy that aims to prevent severe behavioural, emotional and developmental problems in children by enhancing the knowledge, skills and confidence of parents.[45] High satisfaction and positive impact of the program have been reported.[46]

Although the Antwerp experience with Triple P demonstrate that it is not necessary to create new services to obtain positive results, some types of services are not well established at all in children and adolescent mental health care. Respite services, offering short-term, temporary relief to those who are caring for family members, is well developed in disability care but not in CAMHS.

Ultimately formal and informal support systems need to contribute to reinforcing children's and parents' quality of life, skills and confidence. It is a key step in bolstering family and youth involvement in contributing to children and adolescent mental health services, at the policy, management and service level.[17] This has not been a very prominent theme in this participatory research process. Participants were keen to recognize children and families as important stakeholders, to be consulted and informed, but it didn't appear as if they were considered as genuine partners in conceptualizing, initiating, planning and delivering mental health services. The role of the family has been controversial throughout this research process. Participating stakeholders prefer to speak more generically of the 'social entourage' as stakeholders rather than only families, as the latter's interests may not converge with the child's. Dysfunctional families may also be a key cause of the child's mental health problems. Another observation that has been flagged in this research is the absence of both a strong ‘parents of young people living with mental illness’ organization and a youth movement in Belgium to fulfill the role of advocate and systems partner.

5.5.5. Recommendation 5

To strengthen accountability of care providers for children with serious, multiple and complex mental health problems and to expand and reinforce capacity to provide flexible and assertive care in their natural environment.

This recommendation concerns the population of children and adolescents with mental health problems who tend to be hard to reach, or do not fit in the traditional ambulatory or residential services. These situations primarily result from a phenomenon of multiple exclusions rather than having a particular 'disease'. Many of them do not seek and even avoid treatment. Those that do end up in treatment may show themselves uncooperative. These youngsters are often associated with severe behavioral problems. The transgressions acted out through the use of violence against themselves or others are among the 'symptoms' which are the most difficult to handle and often the reason why youngsters are referred onwards. Some of them may have been placed in the juvenile justice system. They have been referred to by the stakeholders as 'the forgotten' or 'the unclassifiable' ('incasables'). A study group of the Institut Wallon de Santé Mentale (IWSM) estimated that about 3 to 5% of the young people admitted to basic youth care (Aide à la Jeunesse) belong to this population.[22]

Stakeholders quite often referred to the challenges of dealing with this group, also in conjunction with the bottleneck in crisis and emergency facilities (see Recommendation 1). The image of 'passing the buck' is also regularly evoked to describe how care institutions deal with these youngsters. It is a population that puts the fragmentation of the mental health care landscape for children and adolescents starkly into relief. The diagnostic analysis that is part of this report has shown that this fragmentation is a result of an interdependent cluster of institutional, sectoral, financial and administrative blockages. These situations ultimately question the place given by the society as a whole to an individual (e.g. the weakening of social ties, changing family configurations, mutation of the norm) and therefore go well beyond the issue of psycho-medico-social care.

Previous studies are, however, largely in agreement on the outline of a service model that increases the opportunities to provide for this 'difficult' group an adequate level of care. Essentially this comes down to establishing an effective platform for mobile, assertive, flexible, networked and multidisciplinary care that is able to reach out to youngsters with complex problems in their natural environment.[10] It is vital that these platforms are able to maintain continuity ('assurer le fil rouge') and take responsibility for a whole care trajectory at the service level. Institutionally, they need to be supported by formalized networks. Actual ways to implement this model may differ from one another in various respects.

For this target group, the National Council for Hospital Facilities[13] recommends a strengthening of 'assertive care' in conjunction with crisis and emergency care. Assertive care is operationalized by a collaboration between residential and ambulatory services and implemented by a multidisciplinary team which can be reinforced by a mobile child psychiatrist if necessary.

The literature review that is included in the first part of this particular study identifies the Wraparound planning process and multi-systemic therapy as documented approaches to dealing with youth suffering from complex mental problems.[9] Both can be considered promising in generating better outcomes for children and adolescents but the scientific evidence is considered as yet inconclusive.[9] Wraparound as a process of arraying multiple services around the child and develop personalized, strength-based care plans is also a central element of the System of Care approach.[9, 14] A multitude of services (crisis, therapeutic, family support) may be offered through a Wraparound approach. One international example discussed in Part I of this study where this kind of mobile and flexible approach has been demonstrated to work well at a regional level is the ESPM Lille-Métropole.[9] Here demands for residential care (and waiting lists) have significantly diminished as a result of activating a quick response mobile team that works in partnership with many regional partners. The team acts as crisis facility, provider of assertive care and liaison function.[9]

There is a multitude of innovative initiatives to dealing with this difficult target group, of which 13 outreach teams (established in Belgium in 2001) are the most conspicuous. Stakeholders are positive about their contribution but they are seen to lack critical mass. Also in forensic care a number of pilot projects have been launched (FOR-K, 2008, see part 1 of this study[9]). In addition, reports[13, 22, 23] refer to initiatives in which various coalitions of youth care, social services and specialized mental health care units are involved. However, these remain small initiatives that are quickly saturated. An example of how, at the end of the line, local experiments in absence of a learning dynamic and a strategic perspective may contribute to the fragmentation they are trying to battle. The report issued by the ISWM therefore argues for the establishment of transversal forums (at a meta-level) to facilitate this kind of learning .[22] This will be further elaborated under Recommendation 7.

Building a critical mass of partnerships and services for children with complex problems clearly confronts the CAMHS systems with a challenge. Stakeholders point out that these kinds of services are expensive and hence require commensurate financing. There is also need for a transparent legal framework to support mobile, flexible and trajectory-oriented work. Deontological matters, financing rules and practical matters of insurance raise questions (for example, how to demarcate assertive care from 'mandatory care'?). Ultimately, though, the challenge is about transcending deep-seated differences between different domains of youth care. It is a matter of accountability and professional ethics. There is need for clear ethical guidelines and a strong, coherent and politically-backed set of incentives to expand the capacity of mobile, persistent and flexible care for this complex target group.

5.5.6. Recommendation 6

To improve cultural and linguistic competences of children and adolescent mental health care providers and youth workers to accommodate the cultural specificities of the populations they serve.

In order to maximize the use of natural supports and facilitate communication between the child and mental health professionals, the availability of adapted linguistic and cultural skills is essential. Linguistic competence comes down to the capacity to communicate in a way that is easily understood by diverse audiences. Cultural competence encompasses the ability to accept and respect diversity and to self assess one's personal perceptions of cultural differences. These competences are essential elements of the value base underpinning the System of Care philosophy.[14]

The increasing diversity of populations, especially in urban areas, has significant implications for CAMHS. The influence of migration on mental health is a matter of debate, but it is an undisputed fact that a proportionally high percentage of children from migrant and refugee backgrounds are being treated in child welfare and juvenile justice facilities (Consultations Flemish Parliament).

Stakeholders point out that medical professionals cannot afford to learn the language of every minority they deal with. On the other hand, services of interpreters don't guarantee a sufficient level of mutual understanding between the professional and the child/family. There is a need for mediators who speak the language but who are also familiar with cultural sensitivities. As a rule in mental health care, mediators need to be physically present. Since the involvement of mediators cannot always be guaranteed, it is important to instill a culturally sensitive attitude in CAMHS practitioners. Particularly in the case of sudden refugee influxes, there should be an instant response capacity, as early intervention is crucial in these cases.

Particular attention should be given to the situation in Brussels, not only because of the extreme heterogeneity of its population, but also considering the linguistic diversity of its institutions and services, which causes additional problems of coordination and collaboration between CAMHS actors, but also of coherence on a governance level.

The overall objective must therefore be to provide a welcoming access to care, by working on the whole environment of the patient and his entourage, to promote the use of networks and devices which enable professionals to take into account cultural, ethnic and linguistic aspects and to ensure that all mental health care services are able to adapt their practice in order to facilitate access and use of services to all children. The promotion of cultural competences is also a guiding principle within the System of Care approach and fundamental to its three core values: community based, family driven and youth guided.

5.5.7. Recommendation 7

a/ To establish a respectful, multilateral dialogue on a shared vision for the broader child and adolescent mental health services system including all relevant stakeholders (including representatives of children and families).

b/ To develop an ethical charter to guide caregivers in formulating answers to the suffering of the child.

c/ To maintain and strengthen cross-sectoral forums at different institutional levels that activate and mobilize collaboration and network formation on an ongoing basis.

The advice on children and adolescent mental health care formulated by the National Council for Hospital Facilities puts forward a number of principles for good care – including a subsidiarity principle and a strength-based and a multi-systems approach - around which its authors join in unanimity. Nevertheless, stakeholders in the present research process frequently referred to important and persistent cultural and professional differences with which they approach their tasks as professionals and managers. These differences are compounded by institutional and legacy factors. The resulting animosities have to be acknowledged.

The move to a mode of a care provision that will increasingly rely on collaborative, networked constellations requires a shared professional and value base to operate from. This has also been pointed out in the KCE-study[11] that evaluated the therapeutic projects as well as in a study carried out by the IWSM[24]on service-level networks in mental health care. Blanket consensus there will never be. But an agreement on key principles and values, mutual respect, and the will to accommodate differences and jointly take responsibility can form the basis for a virtuous circle that leads to better outcomes for children and adolescents and a more fulfilling practice for professionals. This is all the more necessary as care professionals in medical health care are, as a rule, opposed to formalization and standardization as alternative co-ordination mechanisms.

A shared vision on mental health care for children and adolescents not only plays a role at the service level but also at the system level. There is a wide body of experience and research that confirms the importance of a shared vision in system transitions.[25]

Shared professional values ought to be consolidated in an ethical charter. These values are a necessary (but not sufficient) condition to contribute to the wellbeing and development of the young person. But they offer beacons in positioning oneself with respect to the different interests and principles surrounding the suffering child. And they are support and exhortation for professionals to creatively work ('à la marge') with procedural and institutional constraints in the interest of the child. A commitment of each professional to embody these values in his/her cares for the child-supported by a practice of intervision-would consolidate this value base.

Hence there is a need for cross-sectoral forums to deepen these issues. The principles put forward by the National Council advice[13] and the root definition that has been developed as part of this research are a strong foundation to build on. We also think the strong value base underpinning the System of Care approach[14] can offer additional inspiration. Stakeholders acknowledge that these conversations have to take place. They see a 'charter' not as a static framework but as a living document that is embedded in a continuous process of action learning and quality assurance. The UN Declaration of the Rights of the Child[s] and the European Association for Children in Hospitals (EACH) Charter (also called Leiden Charter[t]) were pointed out as potential frames of reference. It could also be integrated into an evolving quality improvement framework, the ultimate aim of which would be to optimize care for the child and to enable creative, professional initiatives in the mental health care sector.

In reflecting upon how to deal with children suffering from complex mental health problems, the ISWM[22] manifestly did not put forward specific models to organize these kinds of mobile and multidisciplinary care but suggested instead to create cross-sectoral forums ('lieux d'activation et de mobilization de la transversalité'), at a meta-level, to function as a persistent invitation to build relations and develop new partnerships. Stakeholders in this process suggested to organise these discussions on clinical cases by mission (outpatient, prevention, residential, etc), and by transversal working groups (including a representative of patients and families, and possibly as needed specialist non-medical expertise such as philosophers).

From a service level it makes sense to calibrate these forums at the scale of 'care basin' given that a shared characteristic of a territory plays a role in the ease with which functional networks are formed. However, from a systems point of view it would certainly be recommended to have a general assembly at a regional or national level. The recommendation is, therefore, to install forums at both levels.

The forums' authority should be consolidated by a braided funding scheme involving partners from mental health care, youth care, disability care and others.

5.5.8. Recommendation 8

To obtain good qualitative and quantitative data of the need for and offering of CAMHS, to effectively leverage regionally distributed care facilities and to facilitate the formation of regional care networks.

Policy makers, care managers and care providers are navigating a complex CAMHS system. A key planning challenge is to obtain good quality data about the type and frequency of demand the care system is confronted with. In Belgium, beyond general prevalence figures, this type of information is hardly available to care managers. Stakeholders refer to long waiting lists to access the services but are aware that these numbers are likely inflated and do not represent reality. Similarly, the size of specific populations (e.g. children and adolescents with complex problems discussed under Recommendation 5) is often not known. Individual institutions will keep a record about the type and frequency of demand but these data are hardly aggregated at a regional or national level.

However, it is very difficult to calibrate the capacity of regionally distributed care services if there is no deeper understanding of the value demand (i.e. demand that is wanted, for which the service is there) and failure demand (demand caused by a failure to do something right for the patient).[26] Some stakeholders are doubtful whether it is possible and even useful to map demand for mental health care and suggest to rely, where possible, on international data to fill the gap.

Beyond demand, there is the challenge to understand what are the genuine needs of the children and families confronted with mental

[s] http://www.unicef.org/crc/

[t] http://www.each-for-sick-children.org/each-charter

challenges are. Stakeholders find it hard to distinguish what is a genuine, articulated need for mental health services from the non-articulated need and from other needs that are not necessarily best served by specialized mental health care. There is a tendency in society to medicalize relatively common psychosocial problems too quickly. Part of the rationale to argue for more supportive and empowering services for children and families (Recommendation 4) lies in bolstering their ability to take an active role in assessing and articulating their needs to counterbalance the weight of fixed routines and protocols. Furthermore, joint assessment of children's needs have been shown to facilitate information sharing and service integration between different sectors and agencies serving this population (see Common assessment framework in the UK.[9]

Not only demand and need are often an unknown quantity, but supply too. Stakeholders have often commented on how difficult it is to keep track of all the facilities that are available in the fragmented and multi-layered CAMHS system. For people who interface with the system like juvenile judges it is even more difficult to navigate. To facilitate the formation of (cross-) sectoral networks there, it is recommended to map available services and capacities at a regional or 'care basin' scale. The activity model and stakeholder mapping included in this study potentially offer a generic template to do so. A first example of this principle are the Flemish "SEN" or Centres for expertise networks,financed by the VAPH, that map available services and capacities at the level of the provinces in the domain of autism (see KCE report part 1 p 66). Again, we refer also to the UK where a Children's services mapping has existed until 2010.[9]

5.5.9. Recommendation 9

To apply and develop evaluation methods based on international best practices, reflecting national or regional specificities and in harmony with ethical guidelines, with the aim to reinforce accountability, professionalism, quality improvement and multidisciplinarity in providing mental health care to children and adolescents.

The use of evaluation methods in mental health care for children and adolescents is controversial. Professionals have been quite outspoken in this participatory research process about their frustrating experience over the last years with policy-driven evaluation methods. Particularly the RPM/MPG (Résumé Psychiatrique Minimale/Minimale Psychiatrische Gegevens) is singled out as burdensome and uninformative. Furthermore, professionals fear that evaluation frameworks will constrain, or be at odds with the therapeutic flexibility they claim is indispensable, given the wide range of mental health problems they are facing and particularly involving children whose needs are known to change as they move along their developmental trajectory.

However, it is acknowledged that today system level management is hampered by the fact that there is no assessment of the overall effectiveness of the CAMHS system. At the service level it is difficult to track progress towards achieving continuous quality improvement without appropriate evaluation methods (see also KCE-report 146).[11]

In other countries similar initiatives have been taken. In the UK the CORC research consortium, of which over half of all services in England are a member, is in the process of developing a common model of routine outcome evaluation. Currently five different scientifically validated outcome measurement instruments are routinely used, e.g. HoNOSCA (Health of the nation outcome scales for children and adolescents).[9]

Stakeholders in this process have suggested a number of important characteristics of evaluation methods:

- Evaluation approaches should be mindful of the complexity of providing care to children and adolescents with mental health problems and stimulate rather than restrain the therapeutic repertoire of care providers;
- Evaluation approaches should in so far as possible be inspired by international best practices. However, they should always be adapted to fit the unique national, regional or local circumstances;
- They should respect the ethical guidelines embodied by an eventual Charter adopted by the community of medical professionals, patient and family representatives and administrators (Recommendation 7);
- Evaluation approaches can only become actionable when there is a genuine sense of ownership by all stakeholders engaged in the process. Hence the importance of developing evaluations in which they are involved in shaping the focus and process of evaluation and are included in the interpretation of results and findings (see also Pires[17]).

Stakeholders' concerns regarding the necessary flexibility of evaluation methods resonate with recent international developments in evaluative practice, notably with the emergence of approaches such as Utilization-focused Developmental Evaluation[27] and Reflexive Monitoring[28]. These are adaptive frameworks that have been developed to assist evaluators and users that are operating in complex, dynamic environments where there is a need for constant innovation and experimentation.

We argue that this kind of framework fits very well the need for complexity-sensitive, situational, ethically guided and participatory evaluation demanded by the CAMHS community. This recommendation connects to all aspects of Recommendation 7 and to Recommendation 8.

5.5.10. Discussion: the recommendations in a strategic change perspective

This participatory research process has given stakeholders the opportunity to reflect on the direction a reform of the children and adolescent mental health services system should take.

A diagnostic analysis has shown that the CAMHS system struggles with a cluster of interdependent problems, the center of gravity of which is a situation of extreme fragmentation and compartmentalization. This is brought about and maintained by a combination of institutional, sectoral, professional and cultural factors. The cost of this fragmentation is arguably significant, both in terms of human suffering and in terms of wasted resources. The very long waiting lists are just one of the more conspicuous indicators of these burdens and inefficiencies.

Stakeholders acknowledge this state of affairs. Over the last decade several system and service level initiatives have been taken to deal with these pressures. However, these innovations have not been able to bolster the adaptive capacity of the system as a whole that remains paralyzed in its predicament. Past failures in collaboratively tackling challenges have resulted in distrust between actors and sectors (mental health care, youth care, disability care, education). Basically, nobody seems to believe in the other's willingness to change. All this points lead to a formidable lock in for which a quick fix cannot be expected. The process of change is likely a lengthy one and this research represents only a modest step along that road.

For stakeholders who have been witnessing the debate in the children and adolescent mental health system for a long time, the recommendations emerging from this research study may seem all too familiar. This can be explained by a number of elements:

- First, as has been indicated earlier (section 2.1.2.) the Soft systems methodology that provides a methodological basis for the study seeks to identify ways to improve a complex, problematic situation that are seen to be culturally and politically feasible by stakeholders. Whilst these interventions may be farsighted, they are usually not truly visionary.
- A second element is that the stakeholder group engaged in this proces to a certain extent overlapped with the expert committee that prepared the National Council Advice. So it is not surprising that there is an overlap in perspectives as well.
- Typical for many of the stakeholders implicated in this research is their resistance to top-down formalization and control. Particularly providers of specialized mental health care fight tooth and claw any attempt to constrain their therapeutic flexibility (see also KCE-report 146[11]). And this is very understandable given the particular and 'messy' nature of their work. The provision of care – basically the activity of improving lives - is always an unruly affair that is difficult to codify.[47] Providing mental health care to children is a particular challenge given the multitude of mental health problems, the child's developmental flexibility and the child's increasingly challenging family and social settings. The upshot is that professionals realize full well that a more joined-up and networked way of working is necessary but that there is little trust in formalizing these networks and creating new functions such as network managers and coordinators. This state of affairs makes it also difficult to find sufficient support for more targeted and tangible recommendations.
- Finally, this research process has primarily focused on a **meso-level** of systems complexity. This is the level of institutional fragmentation. This is framed by a **macro-level** complexity that revolves around the broad philosophical and ethical questions that underly the provision of mental health care. These have been addressed in this research but not in great depth. There is also the **micro-level** complexity in which

the daily life world of the care provider is embedded. This involves the myriad of technical and craft aspects involved in delivering care and the intricate regulatory setting in which the the professional performs (see also 3.2.8.). These elements are hardly ever brought to the table by stakeholders in an interactive process but it can be assumed that they provide numerous starting points to improve the daily experience of patient and professional. Other methods (such as Design for Services[48]) are needed to bring these elements to the fore as a basis for care improvement and reform.

This predicament does not mean, however, that the system is condemned to an interminable and erratic muddling through.

These challenges are in their basic nature not unique. Many large-scale systems in our society – energy and food provision, mobility, to name just a few – are subject to lock-in whilst they face the challenge of a radical change to a more sustainable equilibrium. In recent years, scholars and practitioners in the field of system innovation have developed approaches to facilitate these macroscopic transitions by combining the power of top down and bottom up interventions. 'Transition management', one of these approaches, has been particularly influential in Belgium & The Netherlands in providing a guiding framework for systems innovation, including in health care systems.[25] It revolves around four basic pillars:

- Creating a sense of urgency by exposing the dominant regime's internal contradictions and its vulnerability to environmental pressures;
- Developing a vision of a more effective and sustainable system;
- Initiating and animating a pool of innovative experiments that are coherent with that vision;
- Providing an infrastructure to monitor, evaluate and learn on a continuous basis.

Transition management is not an approach that seeks 'solutions' but is explorative and design-oriented. For CAMHS this underscores the relevance of the System of Care framework which has surfaced in both Part I[9] and Part II of this study as a benchmark of a strategic approach to building an effective and ethically guided children and adolescent mental health system (scientific evidence in favor of System of Care is promising but not conclusive).[9] It has been emphasized that System of Care is not a template method but a general philosophy of how to bring about system change for which six basic elements have to be brought in line (section 4.1.3.3.):

- An overarching strategic approach to systems design underpinned by clear choices as regards target group, desired outcomes, and allocation of resources;
- A clear set of core values and guiding principles to guide the reform;
- An array of design components (from system oversight to coordination and delivery of services to outcome assessment) that are congruent with the basic strategy and core values;
- A practice approach that embodies the core values of a coordinated, individualized, youth-guided and family-driven system;
- An array of evidence-based services and supports;
- A coherent, long-term strategy for system change, leading from pockets of innovation to wide scale adoption of a new model and practice.

Clearly there is a kinship between an approach such as System of Care and the broader field of system innovation framed by influential strategies such as transition management. All of these approaches seek an alignment, a co-evolution between top down and bottom up change in order to avoid the traps of either piecemeal, community-by-community change or blanket technocratic reform.

This research partakes of a similar spirit, without, however, slavishly adhering to any single template. The recommendations that have emerged out of this research process can, however, be very well understood against the background of the systemic change approaches discussed. There are various ways to frame or understand the collection of 9 recommendations. Earlier on they were described as covering three broad substantive areas:

- Recommendations 1 to 4 that want to marshal the demands made on scarce and expensive specialized mental health services for children and adolescents via prevention, empowerment of users and their entourage (families), adequate filtering at first line care services and by strengthening the system's capacity to deal with mental health-related crises.

- Recommendations 5 to 6 focus on strengthening the practice approach of mental health professionals, particularly as regards caring for children who suffer from serious, complex and multiple mental health problems. The proposed recommendations want to plug gaps in accountability in dealing with these young people, reinforce a flexible and assertive approach to providing care for theses children in their natural environment and improve the cultural competences of care providers.
- Recommendations 7 to 9 are targeted towards strengthening the adaptive capacity of and the ethical guidance within the future CAMHS system, via the development of a shared vision, an ethical charter, the application of appropriate evaluation guidelines and efforts to understand the needs for mental health services and the available service offering.

Another, related way to consider these recommendations is to see the first two groups (1-4 and 5-6, respectively) as targeted to improving respectively 'front end' and 'deep end' services and the final group (7-9) as a way to effectuate changes at the system level to support the changes in service delivery. Finally, the recommendations can also be understood against the background of a public health framework, with prevention/early intervention and crisis for all children, specialized services for children with mild to moderate mental health problems (not the subject of a specific recommendation, however) and intensive, assertive services for serious and complex problems. Again, the final three recommendations want to reinforce the system infrastructure to organize and support this.

Taking note of lessons from system innovation and transition management, however, we would caution against seeing this as manifestations of a linear change theory: first improve systems, then improve services, finally improve outcomes. System changes are vital to support the transition to a more effective CAMHS system. Indeed, this research has pointed out how isolated service level innovation, however well intentioned and brilliantly executed, may at some point add to the system's fragmentation and incapacity to adapt. On the other hand, it is important to continue to encourage local experimentation and nurture successes, particularly when they come about through intra-sector or inter-sector partnerships. The knowledge and relational capital harvested through these collaborations is the fuel on which a system wide transformation can thrive. Bottom up and top down dynamics need to reinforce each other. The cross-sectoral platforms of management and accountability advocated in Recommendation 7 are a nodal point where these two dynamics can mesh and reinforce one another through the development of strategic plans, interagency agreements, legislative proposals, funding arrangements and appropriate monitoring and evaluation protocols.

A separate point observed that requires attention is the controversy that exists amongst stakeholders about evidence-based practice. As mentioned above this controversy grounds in the fear that evidence-based practice would undermine the potential for innovation and would lead to a too reductionist approach of financing and evaluating CAMHS. After all, many programs, services and care practices that are used in CAMHS are not yet proven effective, simply because so far no research has been performed yet. However, these programs show promise and/or are believed to be helpful in meeting outcomes important to children, adolescents and their families.[15] Therefore, it is recommended that innovation is promoted by **supporting research programs** within this field. These research programs should stimulate clinical research applying research methods that allow to study the complex interventions that are typically for CAMHS.The research process in the current study has resulted in series of recommendations that frame a medium term agenda for reform and innovation for the Belgian children and adolescent mental health care system. In addition, the study has resulted in a set of systems thinking-inspired instruments that can help the sector to move forward. Finally, there is reason to believe that the intensive discussions between stakeholders within the setting of this process have contributed to increased trust and a shared sense of urgency amongst stakeholders.

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