Centres de réadaptation ORL/PSY: groupes cibles, preuves scientifiques et organisation des soins

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Federaal Kenniscentrum voor de Gezondheidszorg
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Titre : Centres de réadaptation ORL/PSY : groupes cibles, preuves scientifiques et organisation des soins

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PRÉFACE

Les nombreux rapports publiés ces dernières années en Belgique au sujet des centres de revalidation, montrent l'intérêt porté à la prise de décisions rationnelles dans ce secteur. Plusieurs de ces rapports concernent les centres de revalidation ORL/PSY.

Pour ceux qui ne connaissent pas le secteur, cette appellation ORL/PSY peut paraître bizarre. A l'origine, les groupes cibles étaient des patients avec des difficultés d'audition et d'élocution (ORL = Oto-Rhino-Laryngologie) et des troubles mentaux (PSY). Par la suite ces groupes se sont élargis.

L'organisation actuelle de ces centres porte encore le poids de l'histoire. Créés sous l'égide du "Fonds de reclassement social des handicapés", ils ont été transférés en 1991 à l'INAMI. Leur interaction historique avec d'autres secteurs reste cependant grande et des questions se posent dès lors au sujet de la délimitation précise du groupe cible des centres avec ceux d'autres prestataires de soins, comme certains services qui dépendent des départements de l'enseignement.

Ce rapport se penche sur la définition des groupes cibles et sur les fondements scientifiques des traitement qui leur sont apportés. Contrairement aux études précédentes il s'intéresse aussi à l'organisation des soins pour ces groupes cibles à l'étranger et pose la question du rapport coût-efficacité de ces soins. Le lecteur découvrira les réponses qui ont pu être trouvées ainsi que les questions qui restent posées.

Gert Peeters
Directeur général adjoint a.i.

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Directeur généra a.i.

Résumé

INTRODUCTION

Le secteur de la réadaptation en Belgique a fait l'objet d'évaluations par de multiples groupes de travail et de rapports d'études ministériels ou de l'INAMI. Les 45 centres de réadaptation ORL («oto-rhino-laryngologiques») et les 49 centres de réadaptation PSY (PSY= «psychique »), également appelés conventions 9.53 et 9.65 de l'INAMI, constituent l'un des sous-groupes les plus importants. En 2007, ils représentaient pour l'INAMI un budget de 80 millions d'euros, soit 20% du budget de l'INAMI affecté au secteur de la réadaptation. Chaque année, quelque 10.000 personnes (essentiellement des enfants) bénéficient d'un traitement multidisciplinaire dans les centres ORL/PSY. Cela étant, de nombreux autres professionnels dispensent des soins aux mêmes groupes cibles dans d'autres contextes que les centres ORL/PSY.

Deux précédents rapports de l'INAMI ont souligné la difficulté que représente le balisage de la spécificité des groupes cibles des conventions ORL/PSY en comparaison avec ceux d'autres dispensateurs de soins dans d'autres environnements (les orthophonistes, par exemple). Le présent rapport s'efforce d'apporter une réponse à cette question de la spécificité des centres ORL/PSY, en utilisant à cette fin des données émanant de la littérature et des centres eux-mêmes.

OBJECTIFS DE L'ÉTUDE

Des réponses seront apportées aux questions suivantes :

1. Identifier les enfants qui bénéficient d'une réadaptation multidisciplinaire dans les Centres ORL/PSY. Existe-t-il des critères d'inclusion et d'exclusion susceptibles d'être utilisés pour les groupes cibles ORL/PSY ?
2. Quels enseignements peut-on tirer des preuves scientifiques actuelles relatives à la réadaptation psychosociale[a] (multidisciplinaire) pour les groupes cibles ORL/PSY?
3. Qui devrait être responsable de l'organisation et du financement des soins pour les groupes cibles ORL/PSY ? Qui est responsable de l'organisation et du financement de soins similaires dans d'autres pays d'Europe occidentale ? Des soins multidisciplinaires sont-ils disponibles pour ces groupes cibles dans ces pays ?
4. Dans le contexte belge, est-il possible de mener une étude de rentabilité de la réadaptation multidisciplinaire pour les groupes cibles ORL/PSY ?

MÉTHODOLOGIE

Pour répondre à la première question, une analyse a été effectuée en se fondant sur une base de données compilée par la Fédération belge des Centres de Réadaptation ambulatoire. Cette base de données contient des données de 57% des 94 centres ORL/PSY belges et est alimentée par des équipes multidisciplinaires. La base de données renseigne la catégorie de remboursement INAMI ainsi que l'indice CIM-10 (autrement dit, le diagnostic principal), les comorbidités et les troubles connexes pour tous les enfants soignés dans les centres ORL/PSY participants (entre le 1/1/2006 et le 30/6/2006) et pour qui un consentement éclairé a été obtenu. Au total, 4907 enfants (3658 dans les centres néerlandophones et 1249 dans les centres francophones) ont été enrôlés. L'objectif de l'étude était de profiler la population cible des centres.

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[a] On considère comme "réadaptation psychosociale", tous les traitements qui n'impliquent aucune intervention pharmacologique, chirurgicale ou nutritionnelle ou n'ont pas pour objectif d'induire un effet physiologique.

Un examen de la littérature selon les règles de la médecine basée sur les preuves a été réalisé sur les modalités de la réadaptation psychosociale dans l'hyperactivité avec déficit de l'attention (ADHD), les troubles du spectre autistique (TSA), les troubles de l'acquisition de la parole et du langage et les troubles du développement des aptitudes intellectuelles, puisque ces pathologies représentent la majorité des diagnostics enregistrés dans les centres.

Un questionnaire développé par les chercheurs a été rempli par des experts de six autres pays d'Europe occidentale (France, Royaume-Uni, Pays-Bas, Finlande et Suisse) dans le but de préciser la nature et les composantes des soins pour des groupes similaires à ceux des centres ORL/PSY.

Un volet de l'étude décrit l'organisation et le financement des centres ORL/PSY en Belgique dans le but d'analyser leur population et leur dispersion géographique afin de comparer celle-ci à la dispersion géographique d'autres soignants pour lesquels des données similaires sont disponibles.

Enfin, une *étude pilote* a rassemblé les données de 20 centres ORL/PSY choisis de manière aléatoire en ce qui concerne l'évolution et le coût de la réadaptation pour 88 enfants souffrant de troubles du développement/de l'acquisition des aptitudes intellectuelles. Les parents ont donné leur consentement éclairé et ont complété les données en remplissant un questionnaire sur leur perception de l'évolution de leur enfant et sur les coûts supplémentaires.

RÉSULTATS

QUELS ENFANTS BÉNÉFICIENT D'UNE RÉADAPTATION MULTIDISCIPLINAIRE DANS LES CENTRES ORL/PSY?

La plupart des enfants (71.4%) appartiennent à la tranche d'âge des 6-11 ans; les adultes sont rares (2.5%). Les très jeunes enfants et les enfants en bas âge (0-5 ans) ne représentent que 8.4%. Ce sont surtout les enfants qui souffrent de «troubles auditifs» et de "retard mental léger" qui commencent avant l'âge de 6 ans. Seulement 15% des enfants des centres ORL/PSY suivent un enseignement spécialisé.

Selon les résultats de l'étude, la phase de diagnostic dans les centres ORL/PSY est très importante. Pour la plupart des catégories de diagnostic, la plainte principale à l'inscription ne concorde avec le diagnostic clinique que dans moins de 50% des cas.

L'analyse des données de cette étude a montré que 88.4% des enfants pouvaient être affectés à trois groupes: 'retard mental', 'troubles du développement' et 'troubles du comportement'. Les catégories de diagnostic de la CIM-10 les plus utilisées pour le "diagnostic principal" étaient : troubles spécifiques du développement des aptitudes intellectuelles (17.8%), retard mental léger (17.7%), troubles spécifiques de l'acquisition de la parole et du langage (13.5%), troubles envahissants du développement (11.9%) et troubles hyperkinétiques (11.1%). Les catégories de diagnostic les plus fréquentes dans les conventions de l'INAMI étaient : retard mental (21% en ORL, 41% en PSY), fonctionnement intellectuel limité (24% en ORL, 25% en PSY) et troubles de l'apprentissage (20% en ORL, 8% en PSY). Dans la classification CIM-10, au moins une comorbidité ou un trouble connexe a été découvert chez 90% des enfants enrôlés, et 4 sur 6 des troubles comorbides chevauchaient les 6 troubles les plus fréquents dans la classification, ce qui met en exergue qu'un trouble peut être étiqueté comme classification ou comorbidité. Il n'est pas possible de procéder à une comparaison avec la prévalence de ces comorbidités/troubles connexes dans ces groupes cibles en cas de traitement en dehors des centres de réadaptation ORL/PSY et une telle comparaison sortait par ailleurs du champ d'application de la présente étude.

PREUVES SCIENTIFIQUES RELATIVES À LA RÉADAPTATION PSYCHOSOCIALE (MULTIDISCIPLINAIRE) POUR LES GROUPES CIBLES DES CENTRES ORL/PSY

Nous n'avons pas trouvé d'étude portant sur les différences entre le traitement monodisciplinaire et multidisciplinaire ni sur le nombre de disciplines nécessaires pour fournir une réadaptation psychosociale fondée sur des preuves. En outre, nous n'avons trouvé que peu de preuves, voire aucune, sur l'intensité ou la durée souhaitable de la réadaptation psychosociale. La plupart des études se limitent aux troubles principaux, sans tenir compte de la comorbidité : il n'est pas possible de tirer de conclusions sur cette question. On ne dispose pas d'informations sur le traitement dans des tranches d'âge allant au-delà de celles étudiées dans la littérature. Néanmoins, quelques options thérapeutiques et principes généraux intéressants méritent d'être mentionnés.

Hyperactivité avec déficit de l'attention (ADHD)

Les données de plusieurs études scientifiques soutiennent le recours aux traitements comportementaux chez les enfants souffrant d'hyperactivité avec déficit de l'attention. On préconise en particulier l'entraînement de type comportemental pour les parents (généralement en groupe, le cycle compte 8 à 16 séances et se fonde sur des manuels qui décrivent la formation) ainsi que la gestion comportementale au niveau de la classe à l'école. Seules les interventions de type comportemental dispensées de manière très intensive pendant des activités récréatives (ex : camps de vacances) semblent efficaces pour améliorer les relations avec les enfants du même âge. Aucune preuve ne soutient les psychothérapies au cabinet médical en tête-à-tête avec l'enfant ou d'autres thérapies axées sur l'enfant ayant pour objectif d'améliorer les symptômes de l'ADHD (par exemple, des interventions psychothérapeutiques non comportementales comme la ludothérapie). D'autres méthodes thérapeutiques bien connues telles que la psychopédagogie et l'entraînement de la mémoire opérationnelle n'appartenaient pas au champ d'application de la présente étude, mais aucune publication portant sur ces thèmes n'a été obtenue.

Les recommandations de bonne pratique conseillent un entraînement de type comportemental pour les parents, individuel ou en groupe, comme traitement de première instance chez les enfants d'âge préscolaire. Pour les enfants en âge scolaire, l'entraînement de type comportemental pour les parents reste la recommandation la plus importante. Toutefois, on peut aussi envisager une thérapie cognitivo comportementale individuelle ou en groupe, de même qu'un entraînement aux compétences sociales (même si cette option est moins étayée par des preuves).

S'agissant de l'équilibre entre traitement médicamenteux et thérapie psychosociale, un médicament titré *de manière optimale* se distingue par une réelle efficacité pour atténuer les principaux symptômes de l'ADHD à court terme. Pour les enfants d'âge préscolaire, les recommandations de bonne pratique conseillent de ne pas avoir recours au traitement pharmacologique en première instance. Dans le cas des enfants en âge scolaire, la recommandation NICE (2008) préconise les médicaments en première instance dans les cas sévères uniquement, tandis que SIGN (2005) en fait le traitement classique en première instance.

Dans les mécanismes de fonctionnement qui ne relèvent pas de l'ADHD, comme le comportement agressif ou la relation parent-enfant, l'association du traitement médicamenteux et de la thérapie comportementale est sans doute plus efficace que l'une de ces deux options isolément (des recherches ultérieures sont nécessaires). Les recommandations préconisent dès lors de toujours d'associer un traitement médicamenteux à un entraînement parental et/ou une implication des enseignants.

Troubles du spectre autistique (TSA)

Certains principes de la réadaptation psychosociale sont prometteurs chez les enfants souffrant de TSA. Primo, les difficultés complexes inhérentes aux TSA requièrent une prise en charge multimodale comprenant un soutien aux parents, leur implication et une composante axée sur l'enfant. Les interventions comportementales et pédagogiques, notamment l'analyse du comportement, ont prouvé leur utilité incontestée dans le programme d'intervention pour les TSA. Secundo, il paraît important d'identifier les enfants atteints de TSA le plus rapidement possible afin d'entreprendre au plus vite les interventions adéquates. Toutefois, aucune étude n'a, à ce jour, comparé les résultats entre le diagnostic et le traitement précoces versus un diagnostic et une prise en charge plus tardifs. Tertio, des preuves tangibles indiquent que les interventions devraient être personnalisées et fondées sur les points forts et les besoins de l'enfant et de sa famille. Des recommandations récentes confirment ces conclusions.

Troubles de l'acquisition de la parole et du langage

Les conclusions que l'on peut tirer de la littérature scientifique concernent l'efficacité réelle des interventions au niveau de la parole et du langage chez les enfants présentant des troubles de l'expression orale. En revanche, les effets chez les enfants qui souffrent de troubles du langage de type réceptif sont minimes, voire absents.

En général, on n'observe aucune différence entre l'intervention de parents ayant suivi une formation et celle de cliniciens en tant qu'administrateurs des interventions. Certaines études laissent entendre que les interventions par les parents sont plus efficaces. On ne rapporte aucune différence entre la thérapie individuelle et la thérapie de groupe.

Troubles spécifiques des acquisitions scolaires

Il existe des preuves scientifiques selon lesquelles certains principes devraient être inclus dans les programmes de lecture pour les enfants dyslexiques : par exemple, leur enseigner le principe alphabétique (à un groupe de lettres écrites ou graphème correspond un son ou phonème). Chez les enfants présentant des troubles mathématiques, aucune conclusion ne peut être tirée en raison du nombre limité d'articles obtenus.

QUELS CRITÈRES D'INCLUSION ET D'EXCLUSION UTILISER DANS LES CENTRES ORL/PSY?

Comorbidités et troubles connexes dans la population ORL/PSY: une aide limitée pour trancher entre traitement monodisciplinaire ou multidisciplinaire

Dans le contexte du remboursement, nous n'avons pu trouver aucune définition claire de la mission spécifique des centres ORL/PSY par rapport aux autres dispensateurs de soins appartenant à leur réseau. En règle générale, les centres ORL/PSY sont établis pour prendre en charge une population plus complexe par rapport aux soignants qui travaillent de manière monodisciplinaire.

On pourrait émettre l'hypothèse selon laquelle la complexité de certains troubles du développement est définie par le nombre et la nature de leurs comorbidités ou troubles connexes. Toutefois, l'analyse des données n'a pas confirmé cette hypothèse puisqu'elle n'a pas pu dégager d'association claire entre le nombre et la nature des différentes thérapies par patient et le nombre ou type de comorbidités et/ou troubles connexes. Enfin, les catégories diagnostiques comme les TSA ou les troubles des apprentissages impliquant plusieurs domaines d'apprentissage peuvent se révéler complexes, même en l'absence de toute comorbidité.

En conclusion, l'enregistrement des comorbidités et des troubles connexes fournit un tableau plus précis des problèmes du patient, mais ne mène pas à une meilleure prise de décision s'agissant du traitement monodisciplinaire ou multidisciplinaire ni à un meilleur financement.

Comparaison entre la codification INAMI et la CIM-10

Les codifications de l'INAMI se fondent sur la CIM-10. L'analyse des données a mis en évidence un important chevauchement entre les deux systèmes : les six principales classifications de la CIM-10 possèdent leur équivalent manifeste dans le système de conventions de l'INAMI. Cela étant, on observe aussi des différences importantes dans les classifications des groupes et des patients.

D'abord, la catégorie "Fonctionnement intellectuel limité" dans les conventions de l'INAMI (fourchette QI 70-84, enregistrée chez 25% des enfants), appartient dans la CIM-10 à la catégorie résiduelle R41.8 (enregistrement chez 22%) qui n'est pas considérée comme trouble en tant que tel. Dans la CIM-10, les personnes dont le QI se situe dans la fourchette 70-84 peuvent être classifiées selon un diagnostic principal de «troubles du développement», ce qui n'est pas autorisé par les conventions de l'INAMI. D'autre part, les définitions de la CIM-10 pour "troubles du développement des aptitudes intellectuelles ou de l'acquisition de la parole/du langage» comprennent un fonctionnement à ou en dessous du troisième percentile à âge et QI donnés. Ceci implique que si l'on utilisait les définitions de la CIM-10 pour le remboursement, il serait plus difficile pour les personnes dont le QI se situe dans la fourchette 70-84 d'obtenir un remboursement par rapport à celles dont le QI est supérieur à 84.

Par ailleurs, le pourcentage de patients confinés dans une certaine catégorie révèle d'importantes différences entre les deux systèmes de classification. À titre d'exemple, 50 à 60% seulement des enfants appartenant aux catégories "troubles du développement des aptitudes intellectuelles", "troubles hyperkinétiques» ou " troubles envahissants du développement" font partie de leur catégorie correspondante dans le système de l'INAMI. Ce pourcentage est encore inférieur pour les enfants de la catégorie CIM-10 "troubles de l'acquisition de la parole et du langage" (20%).

La différence de classification des patients n'est pas facile à expliquer, mais une cause pourrait être un «surclassement» ou une «optimisation» motivés par des avantages en matière de remboursement. Effectivement, les codes de l'INAMI "Retard mental" et "Fonctionnement intellectuel limité" sont très souvent utilisés pour traduire les codes CIM-10 non correspondants, et ces deux codes de l'INAMI représentent les deux conditions de remboursement les plus favorables.

La comparaison ci-dessus n'apporte en fait aucun élément permettant de conclure qu'une modification de la classification INAMI pourrait conduire à un meilleur système de financement.

ORGANISATION ET FINANCEMENT DES SOINS MULTIDISCIPLINAIRES POUR LES GROUPES CIBLES ORL/PSY

Organisation des soins dans 6 autres pays occidentaux

Malgré l'absence de preuves scientifiques, les six pays occidentaux étudiés offrent un traitement multidisciplinaire pour les troubles envahissants du développement, les troubles hyperkinétiques et les troubles spécifiques des acquisitions scolaires et de l'acquisition de la parole/du langage. Le traitement multidisciplinaire est standard dans tous les pays pour les deux premiers troubles et est souvent, mais pas toujours, disponible pour les deux derniers. Toutefois, ces traitements ne sont pas dispensés dans des contextes similaires à celui des centres belges ORL/PSY, mais plutôt dans le cadre du système d'enseignement, en pédopsychiatrie, en pédiatrie ou dans le système privé. Autre différence : dans de nombreux pays, «multidisciplinaire» ne signifie pas «trois disciplines ou plus» mais bien «deux disciplines ou plus».

Comme en Belgique, dans la plupart des pays, le système de soins de santé (et social), de même que le système d'enseignement assurent le financement (d'une partie) du traitement multidisciplinaire. Il existe des différences entre les catégories 'troubles envahissants du développement' ou « troubles hyperkinétiques», d'une part, et « troubles spécifiques des acquisitions scolaires» ou 'troubles spécifiques de l'acquisition de la parole et du langage', d'autre part. Ces deux dernières catégories relèvent davantage de la responsabilité de la filière enseignement.

Organisation des centres ORL/PSY en Belgique

Répartition inégale en Belgique

La répartition des centres ORL/PSY et du budget annuel par tête est inégale entre les provinces belges et le budget par tête est deux fois plus élevé en Flandre qu'en Wallonie. Cette situation est probablement due au moratoire de 1987 sur la création de nouveaux centres de réadaptation. Autre explication : une offre plus importante de services de remplacement (orthophonistes privés, éducation spécialisée avec ou sans (semi-)internat, centres de santé mentale) dans les régions dotées d'un nombre moindre de centres de réadaptation. Cette hypothèse n'a pas été confirmée par les constats de la présente étude.

Différences entre ORL et PSY et entre les centres francophones et néerlandophones

Il existe quelques différences entre les populations de patients des centres ORL et PSY, notamment en ce qui concerne le 'retard mental léger' (14% ORL, 22% PSY) et les 'troubles du développement des aptitudes intellectuelles' (24% ORL, 11% PSY). Toutefois, dans l'ensemble, ces différences entre les populations de patients sont limitées. Ainsi, les cinq classifications de troubles les plus fréquentes de la CIM-10 représentent respectivement 75% et 69% dans les centres ORL et PSY. Les groupes cibles ORL spécifiques de l'INAMI et les groupes cibles PSY spécifiques de l'INAMI ne représentent qu'une part mineure de l'échantillon de population (15.6% dans les centres ORL, 6.9% dans les centres PSY).

Des différences existent au niveau des codifications diagnostiques entre les centres néerlandophones et francophones mais il faut tenir compte du fait que les centres ORL francophones de l'échantillon ne sont peut-être pas tout à fait représentatifs. A titre d'exemple, les codifications CIM-10 des «troubles spécifiques des acquisitions scolaires»' et des « troubles hyperkinétiques » sont plus fréquentes dans les centres PSY néerlandophones que dans les centres francophones. A l'inverse, la codification de l'INAMI « retard mental » est moins fréquente dans les centres néerlandophones que dans les centres francophones.

Étude pilote sur la faisabilité d'études de rentabilité dans les centres de réadaptation ORL/PSY

Par définition, une étude de rentabilité pour les groupes cibles ORL/PSY n'est pas possible, car il n'existe pas de données relatives à leur efficacité réelle. Néanmoins, une étude coûts-résultats a été réalisée pour le groupe « troubles spécifiques des acquisitions scolaires ». Les enseignements tirés de cette étude de faisabilité montrent que mesurer l'évolution des résultats sur base des rapports fournis pas les centres de réadaptation achoppe sur des difficultés méthodologiques. Des mesures plus uniformes des résultats sont notamment nécessaires, de préférence en incluant tous les domaines de la CIF[b]. De même, un lien avec les résultats de l'enfant durant le suivi devrait permettre de déterminer si les bénéfices persistent après le traitement. Idéalement, on devrait comparer l'évolution des résultats chez les enfants suivis dans les centres ORL/PSY à celle des résultats d'enfants présentant des problèmes similaires, mais pris en charge dans d'autres contextes (par exemple, traitement monodisciplinaire, environnement scolaire, etc.). Cette comparaison permettrait de se faire un jugement sur la valeur ajoutée spécifique des centres de réadaptation ORL/PSY.

Une conclusion prudente de cet échantillon pilote restreint est que certains gains ont été obtenus au niveau des aptitudes scolaires (0-11 percentiles pour une année de traitement), quoique l'importance clinique de ce bénéfice soit difficile à interpréter. Les parents rapportent une amélioration du fonctionnement et de la confiance en soi. Au niveau des coûts, les parents déclarent de multiples coûts d'opportunité (par exemple, frais de transport, perte d'heures de travail). Dans l'environnement scolaire, une somme de temps supplémentaire importante est consacrée à ces enfants.

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b CIF: Classification internationale du fonctionnement, du handicap et de la santé. Cette classification est avalisée par l'OMS en tant que cadre conceptuel visant à décrire le « degré d'invalidité » d'une personne, et est considérée comme complémentaire de la classification CIM ((www.who.int)

Dans une large mesure, la charge financière est financée par la société : le coût mensuel du traitement de réadaptation est de 643 euros pour les pouvoirs publics (INAMI) ; pour les parents, le coût médian se monte à 14 euros par mois.

RECOMMANDATIONS

Le KCE formule les recommandations suivantes pour les centres ORL/PSY :

En relation avec la prise en charge :

1. Pour les enfants souffrant d'ADHD et les enfants souffrant d'un trouble du spectre autistique :
    - S'assurer que les traitements soient en accord avec les principes du traitement fondé sur les preuves c-à-d :
        - Pour les enfants ADHD, l'entraînement parental de type comportemental soit individuel, soit en groupe, constitue la pierre angulaire du traitement psychosocial ;
        - Pour les enfants souffrant d'un trouble du spectre autistique, une approche multimodale doit inclure une composante axée sur l'enfant tout en une composante soutenant/impliquant les parents ;
2. Pour les enfants présentant des troubles de l'acquisition de la parole/du langage et des troubles spécifiques des acquisitions scolaires, ce rapport n'a identifié aucune preuve scientifique en faveur d'une prise en charge multidisciplinaire. Le KCE recommande dès lors :
    - De considérer l'ensemble des interventions dont pourraient bénéficier ces enfants et leurs parents, non seulement dans les centres NOK/PSY mais également dans d'autres contextes de soins (e.a. traitements monodisciplinaires) ou dans le contexte de l'enseignement (cf. exemples internationaux) ;
    - De réfléchir à l'évolution souhaitable de la prise en charge de ce type d'enfants sur base d'études scientifiques à entreprendre, comme par exemple :
        - Des études qui incluraient des enfants traités dans d'autres types de services de soins de santé (par exemple monodisciplinaires) de même que des enfants pris en charge en dehors du système de soins de santé (par exemple à l'école) dans le but d'objectiver la valeur spécifique ajoutée de la réadaptation ORL/PSY ;
        - Des études de comparaison de résultats et de coûts entre le système belge et les systèmes étrangers ;
    - De faire dépendre la poursuite du financement des centres pour les sous-groupes d'enfants présentant des troubles de l'acquisition de la parole/du langage et des troubles spécifiques des acquisitions scolaires à la participation de ces centres à de telles études.

En relation avec l'organisation générale des centres ORL/PSY :

- De mettre au point un enregistrement standardisé des activités des centres ORL/PSY : les données essentielles incluent non seulement le profil et les diagnostics des enfants mais également le nombre et la nature des traitements, les soignants impliqués et les interventions simultanées en dehors du centre (e.a. à l'école) ;
- D'enregistrer les résultats des interventions en utilisant des outils validés de préférence incluant tous les domaines significatifs du fonctionnement de l'enfant ;

- D'abolir la distinction actuelle entre les conventions ORL et PSY;

En relation avec le remboursement :

- De maintenir les catégories actuelles de la classification de l'INAMI pour le remboursement dans les centres ORL/PSY;
- De reconsidérer, au sein des catégories INAMI existantes, les critères de remboursement afin de minimiser les misclassifications causées par des avantages liés au remboursement ; cette recommandation est particulièrement d'application pour les catégories « Fonctionnement intellectuel limité » et « retard mental »;
- Dans la même optique, améliorer le processus d'accord pour le remboursement par les organismes assureurs;
- De coupler les demandes de remboursement à l'enregistrement standardisé précité.

En relation avec des recherches futures :

- D'étudier l'offre de soins actuelle pour les enfants appartenant aux groupes cibles NOK/PSY mais résidant dans des régions qui n'ont pas ou peu de centres NOK/PSY; cette étude approfondie devrait être décisive quant à la nécessité d'une offre de soins supplémentaire pour ces enfants ;
- D'étudier la valeur ajoutée d'un coordinateur de soins, qui coordonne les multiples interventions reçues par ces enfants dans différents contextes et/ou à différents moments ; cette étude pilote évaluerait également la faisabilité d'une coordination pour ces enfants au sein des différents contextes belges tant le contexte des soins de santé et que les contextes autres que celui-ci.

Scientific Summary

TABLE OF CONTENTS

INTRODUCTION

This study deals with the multi-disciplinary treatment in 'NOK/PSY' rehabilitation centres of children, adolescents, and- sometimes- adults. These centres were first established in 1968 for the rehabilitation of children with psychic developmental disorders ('PSY') or hearing disorders ('NOK'/'OP': 'neus-oor-keel/ouïe et parole), but soon a significant diversification and growth of target groups developed. According to the federal Belgian law each centre has a convention with the institute of the national health care, the 'Rijksinstituut voor ziekte- en invaliditeitsverzekering' (RIZIV)/'Institut national d'assurance maladie-invalidité' (INAMI) (National Institute for Health and Disability Insurance). On the other hand: their legal recognition (e.g. safety and quality standards) belongs to the regional governments: the Walloon provinces, Flanders and Brussels.

Since a long time there is confusion about the specific goals and identity of these centres: what is the difference with e.g. speech therapy, guidance centres for disabled people, psychiatric services or the 'classic', "locomotor" or physical rehabilitation? There is also little known about the outcome of this kind of rehabilitation, the costs, the specificity of 'NOK' and 'PSY' centres, the atypical regional distribution, possible regional differences in target groups, their specific aims and working characteristics in relation to other caregivers, etc.

This study aims to clarify some aspects of the tasks and nature of NOK/PSY centres, providing an answer to the following questions:

What are the main working characteristics, regulations and the regional accessibility to the Belgian NOK/PSY centres? These questions are answered in the first part

Which children (or adults) receive treatment in the NOK/PSY centres? This question is clarified in the second part. A retrospective analysis was performed on a database collected by the Belgian 'Federatie van Centra voor Ambulante Revalidatie'/'Fédération des Centres de Réadaption Ambulatoire'. This database contains not only the RIZIV/INAMI reimbursement category but also the ICD-10 codification on children treated in 57% of the 94 Belgian NOK/PSY centres. By comparing the RIZIV/INAMI reimbursement system to the ICD-10, which is an internationally well-accepted diagnostic classification system, a more precise description of the NOK/PSY target groups is aimed at.

What are the evidence-based treatment methods for the main target groups of NOK/PSY rehabilitation centres? In the third part, a literature study on ADHD, autism spectrum disorders, and language or learning disorders was performed, and the rules of EBM (Evidence Based Medicine) were strictly applied in order to gather only this information which complies with high research standards of measuring efficacy/efficiency. The number of resulting publications is not spectacular. This may be due to low-level investments in this kind of research, or –paradoxically- to the complexity of the required methodology.

Who should be responsible for organisation and financing of the care for the NOK/PSY target groups? Who is responsible for organisation and financing of care in other Western European countries, and is multidisciplinary care for these target groups available in these countries? To answer this question, experts from the Netherlands, France, Germany, the United Kingdom, Finland, and Switzerland filled out a questionnaire developed by the research team. The results are presented in the fourth part.

What is the cost-effectiveness of multidisciplinary rehabilitation for the NOK/PSY target groups? Is it feasible in the Belgian context to conduct cost-effectiveness studies for multidisciplinary rehabilitation of developmental disorders? This question is handled in the fifth part, where the results are presented of a pilot study on a limited number of children with developmental disorders of scholastic skills.

Notwithstanding the interesting results of this study, other compelling questions and research topics remain to be addressed, e.g., the need for outcome research, the implementation of evidence-based treatment in the rehabilitation centres, the study of the relationship between categorical diagnosis and reimbursement and how to make a thorough analysis of the complex federal and regional organisation of medical-psychosocial care in Belgium.

1 CHARACTERISTICS OF BELGIAN NOK/PSY[a] REHABILITATION CENTRES

1.1 INTRODUCTION

This part of the report deals with the development of rehabilitation centres, the legal framework, the main characteristics of NOK/PSY rehabilitation centres (target groups, core tasks and work practice), the geographic distribution and the financing system.

1.2 DEVELOPMENT OF NOK AND PSY REHABILITATION CENTRES IN BELGIUM

In Belgium, rehabilitation has its origin both in the aftermath of the World Wars with their victims who needed to be reintegrated in society and in the fast-growing economy in the sixties. The aim was to get these people back to work after a period of rehabilitation. Rehabilitation was based on the principle of making people fit again and promote productivity. The freedom and economic growth after these wars made free initiatives possible. The concept of rehabilitation liberalised to other fields than work namely social reintegration, medical and educational rehabilitation.

The 'Rijksfonds voor Sociale Reclassering van Minder-Validen'/le 'Fonds national de reclassement social des handicapés' (1963) [b] was established to provide a legal framework for these free initiatives. This framework recognised six different kinds of rehabilitation centres (centres for loco-motor disabilities, motor-cerebral/neurological disabilities, cardiological disabilities, speech and hearing disabilities, psychological disabilities and for visually impaired persons). PSY centres are subdivided into PSY 4 (adolescents and adults with psychiatric problems) and PSY 5 rehabilitation centres (children). Because this project is limited to rehabilitation centres concerning speech and hearing rehabilitation (NOK) and psychological rehabilitation (PSY) for children, the other types of rehabilitation centres will not be discussed. The RIZIV ('Rijksinstituut voor ziekte- en invaliditeitsverzekering') / INAMI ('Institut national d'assurance maladie-invalidité') (National Institute for Health and Disability Insurance) (see Appendix to Chapter 1) took over the responsibility for this kind of rehabilitation in 1991 (see further in this chapter). The last decade PSY and NOK centres became very alike (see Chapter 2 Data analyses).

The first NOK rehabilitation centre started in 1968 and other centres followed rapidly. The 'Federaties van Revalidatiecentra' were founded and became a confederation of 5 different federations according to the type of the rehabilitation centre. The federations of NOK and PSY centres had a close cooperation and were unified in 2004. Although most of the NOK and PSY centres are extramural (ambulatory), intramural care also exists. These centres are integrated in hospitals. This project is limited to the ambulatory NOK and PSY rehabilitation centres [1;2].

Since 1987 a moratorium on new legitimisations of rehabilitation centres exists. An exception to that rule was made in 2001 when 3 additional centres under agreement of the RIZIV, were recognised (RIZIV, 2001).

The next chapter will define the legal characteristics of the Belgian rehabilitation centres. These play an important role in the development and evolution of the centres.

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a NOK= "Neus-Oor-Keel", OP="l' Ouïe –Parole" (speech and hearing disorders), further in this report the term NOK is used
PSY= "psychisch"-"psychique' (psychological disorders)

b The department responsible for the social resettlement of persons with a handicap

1.3 LEGAL CHARACTERISTICS OF THE BELGIAN REHABILITATION CENTRES.

1.3.1 In general

The organisation and financing of rehabilitation in Belgium is very complex and heterogeneous; and to clarify the situation, some aspects of the Belgian political and geographical situation need to be discussed. The federal government is responsible, independent of language, cultural or territorial issues, for foreign affairs, national defence, law, financing, social security, health care, internal affairs and for all issues concerning the European Union and the NATO. Belgium contains three language communities *(taalgemeenschappen/communautés linguistiques)* namely the Flemish, the French and the German community. These are responsible for issues concerning citizens (for example educational, personal and cultural issues, e.g. the language spoken in health care). Belgium also consists of three regions *(gewesten/régions)*: the Flemish region, the Walloon region and Brussels. These are responsible for economical policies e.g. transport and for global policies like environmental planning.

In January 1991, the federal 'Rijksfonds voor Sociale Reclassering van de Mindervaliden'/'Fonds national de reclassement social des handicapés' that regulated and financed all aspects of the rehabilitation facilities, was dissolved due to Belgian political defederalisation. From then on, rehabilitation became the responsibility of the RIZIV/INAMI (a national institution) and community institutions, e.g. the 'Vlaams Agentschap voor Personen met een Handicap' (VAPH)/'Association Wallonne pour l' Integration des Personnes Handicapés' (AWIPH). The unequal distribution of the centres that existed at that moment throughout Belgium, as well as some regulatory inequalities between the centres, were adopted by these agencies. Legitimization, infrastructure and equipment became the main responsibility of the communities and the cost of the rehabilitation itself became a national (federal) responsibility (reimbursement of the claimants by the National Health Services). Relatively, the rehabilitation centres receive most of their incomes of the health care department (Desnerck, 2004).

1.3.2 The level of the communities

Organisation

The federal government outsourced all personal related issues such as the support of disabled people to the regions or communities. The Flemish community contains the **VAPH** (Vlaams Agentschap voor Personen met een Handicap), the Walloon region contains the **AWIPH** (Agence Wallonne pour l'intégration des personnes handicapés) and the German community contains the **DPB** (Dienststelle für Personen mit Behinderung). In Brussels, there are 3 structures responsible: the COCOF (Commission communautaire française) (the French community) contains the **SBFPH** (Service bruxellois francophone pour des personnes handicapées), the VGC (Vlaamse Gemeenschapscommissie) (the Flemisch community) passed this responsibility to the **VAPH** and finally, the **GGC/COCOM** (Gemeenschappelijke gemeenschapscommissie/Commission communautaire commun) support directly the bilingual institutions. The three communities receive their funds form the federal government and pass it to their 3 agencies (VAPH, AWIPH, DPB). Further, the French community funds the COCOF to finance their agency (SBFPH). The GGC /COCOM receive funds from the Flemish and the French community[c.]

VAPH/AWIPH/DPB/SBFPH aims to promote integration, participation and equal opportunities for people with a disability in all areas of social life. Their ultimate goal is to help them lead a better and more independent life, by subsidizing facilities and by offering special services (for example the rehabilitation centres)[d.]

c http://www.dernier.be/dnr/n/Manifest%20NL-FR.pdf
d http://www.vlafo.be/vlafo/view/nl/204713-en.html

The financial involvement of the VAPH/AWIPH/BPD in the rehabilitation centres is significantly smaller than the former federal 'Rijksfonds voor Sociale Reclassering van de Mindervaliden'/ 'Fonds national de reclassement social des handicapés'.

Due to the take-over of the rehabilitation costs by the RIZIV/INAMI, rehabilitation centres are less prominent in the VAPH/AWIPH/DPB then other institutions (for example MPI's (Medisch Pedagogische Instituten)/IMP[e] (Institut Médico-Pédagogique) (Medical Pedagogical Institutions)).

1.1.2.3. The national/federal level: RIZIV/INAMI

The RIZIV/INAMI is a federal institution responsible for health care and it organizes, manages and supervises the application of the compulsory insurance in Belgium. This institution is supervised by the Minister of Social Affairs.

The work practice of the rehabilitation centres is set out in the RIZIV/INAMI-conventions which became effective in 1996. Different conventions were generated for NOK and PSY rehabilitation centres (see Appendices to Chapter 1) in which the target groups, practices about the rehabilitation programme, the way of creating invoices, a prohibition of accumulation of care and provisions concerning the staff are regulated. Each centre has a budget based upon the operational costs (except for these covered by the VAPH/AWIPH). This budget must cover the personnel and general costs (Desnerck, 2004).

Main obligations and regulations of the RIZIV/INAM

The RIZIV/ INAMI formulated certain obligations for the rehabilitation centres in order to invoice the costs (see Appendix to Chapter 1).

First, the rehabilitation centres can invoice activities concerning diagnosis. The diagnostic process can not last longer than two months. Therapy can not take longer than 12 months but this can be renewed. To get this renewal, the centre has to send an extensive report to the medical adviser of the sickness fund in order to get his approval.

For each target group (see 1.1.3.1), a maximum rehabilitation period is formulated. This period is widely divergent according to the target group and reflects the complexity of the disorder(s) (for example 'mental retardation' is unrestricted until the age of 6 and from the age of 7 until 18 the period is restricted to 6 not consecutive years, for 'developmental disorders of scholastic skills', the maximum period is restricted to 2 consecutive years).

Second, a therapy session needs to take minimum 1 and maximum 2 hours a day. This maximum concerns the financial compensation. Rehabilitation centres can decide to provide more than two hours of treatment a day. Partial sessions need to take at least 30 minutes each, so several kinds of disciplines can be cumulated in order to get 1, 1,5 or 2 or more hours of therapy. Sessions can be organised individually or in group.

Therapy in a rehabilitation centre can, generally speaking, not be combined with private therapy. The accumulation of private speech therapy and rehabilitation is always impossible. Exceptions are made for certain kinds of private physical therapy and medical services.

Third, the convention describes the personnel. The team must be multidisciplinary and contains regularly one or more physicians, psychologists, speech therapists, physiotherapists, occupational therapists and social workers or social nurses. NOK rehabilitation centres have commonly more speech therapists than PSY rehabilitation centres (Desnerck, 2004).

Finally, rehabilitation can only be reimbursed when at least three different team members, with a different discipline, provide monthly face-to-face treatment or consult and when there are at least two consultations a year provided by a physician member of the rehabilitation team.

e Since October 1997: '*services d'acqueil' or 'services résidentiels pour jeunes (SRJ) ou pour adultes (SRA)'*

Each rehabilitation centre has a maximum capacity of 'forfeits': the number of face-to-face activities (diagnostic or therapeutic; with the child and/or the parents) depending on the size of the team[f] and based on the assumption that therapeutic working time contains 70% face-to-face treatment or diagnostic activities and 30% other activities (such as working together with other caregivers, school visits, team meetings, administration etc).

The working costs are determined as 15% of the total costs for personnel (in order to economize, working costs are presently detached from the costs for personnel).

The total cost (personnel cost and working costs) divided by 90%[g] of the maximum capacity ('forfeits') fixes the lump sum the centre receives per forfeit. This lump sum includes a refundable part (refunded by National Health Services) and a fixed non refundable part (€1.54 € at the expense of the patient himself). If the centre does not realise 90% of its maximal forfeit capacity per year, it receives less money than necessary to cover the operational costs; if the centre goes beyond this number, the price for one forfeit goes gradually down [3;4].

1.4 MAIN CHARACTERISTICS OF NOK/PSY REHABILITATION CENTRES

The 'Raad van Europa' (1992) defines 'rehabilitation' as the interdisciplinary combination of techniques to improve the functional prognosis and to improve the prognosis of disabilities leading to local or general pathological effects. In the article of Maes (1999) another definition for the Flemish 'Centra voor Ambulante revalidatie' (CAR) is used: "Rehabilitation is a process of interdisciplinary diagnostic and therapeutic interventions for people with a disability and their environment. It aims at recovery or improvement of functional/structural disabilities, more adequate personal functioning, higher participation of that person in different life situations, and a better harmony between the patient and his environment" [5].

Rehabilitation centres provide second line care and can only by referred to by a private physician or a physician working in a CLB/PMS (Centrum voor Leerlingenbegeleiding/Centres psycho-médico-socio (school guidance services).

Target groups, functions and a minimum of quality criteria for the practice within rehabilitation centres are described in the next chapter.

1.4.1 Specific target groups

Various people with different disabilities, problems and questions can be referred to rehabilitation centres for multidisciplinary diagnosis and for treatment. For diagnosis patients must be referred by a physician. As far as treatment concerns, a basic condition is that the severity of the disorders necessitates an intensive multidisciplinary rehabilitation. The conventions of the RIZIV/INAMI define from which level on (based on percentile scores of outcome measures) a certain disability can be considered severe enough to receive reimbursement for intensive multidisciplinary rehabilitation.

Furthermore, each patient needs to be classified in one of the target groups described in the RIZIV/INAMI NOK or PSY convention (see Appendix to Chapter 1 for the NOK convention and for the PSY convention). The NOK convention contains 13 different target groups, whereas the PSY convention describes 12. From these , 8 are common in both conventions (although with a different group number): 'Brain damage' (group 1 in both conventions)[h]; 'Mental retardation IQ < 70' (group 7 in NOK, group 2 in PSY); 'Autism spectrum disorders' (group 8 in NOK, group 3 in PSY);

f To calculate the forfeit, the psychologists/ licentiates in educational sciences and social workers/nurses are included for only 50%, because they are more than other team members involved in contextualizing activities (contacts with the network, reporting…). Physicians are not included to calculate the price of one forfeit.

g To take 10% absence of personnel and patients into account.

h The ICD-10 can be consulted in order to get more detailed information concerning the definition of the mentioned disorders. (ICD-10 Bluebook). Autism spectrum disorders are a synonym for pervasive developmental disorders.

'Language developmental disorders' (group 9 in NOK, group 8 in PSY); 'Borderline intellectual functioning (IQ between 70 and 84) with harmonic or disharmonic profile' (group 10 a and 10b in NOK, group 9a and 9b in PSY); 'Developmental disorders of scholastic skills' (group 11 in NOK, group 10 in PSY); 'Hyperkinetic disorders' (group 12 in NOK, group 11 in PSY) and 'Stuttering' (group 13 in NOK, group 12 in PSY).

In both conventions, several specific target groups are described, which only appear in the NOK or the PSY convention. Exclusive target groups in the NOK convention are: 'Laryngectomy, glossectomy' (group 2); 'Hearing disorders in the pre- or perilingual phase' (group 3); 'Hearing disorders >70dBA, after the 6th and before the 19th anniversary' (group 4); 'Hearing disorders >40dBA, after the 6th anniversary' (group 5) and 'Hearing disorders with cochlear implant' (group 6).

The following target groups appear in the PSY convention only: 'Severe conduct disorders' (group 4); 'Schizophrenia' (group 5), 'Mood disorders' (group 6) and 'Cerebral palsy' (group 7). In this convention the age of the patients is limited to 19 years.

Not all rehabilitation centres treat all target groups. This is depending on the regional organisation of healthcare.

1.4.2 Core tasks

Diagnostic functions

The diagnostic research aims at clarifying the nature, type and seriousness of the disorder, the consequences of the disorder on the daily functioning of the patient, his restrictions as well as developmental possibilities and environmental factors that restrict or facilitate this development. The ultimate goal is formulating well-grounded indications for care (which and by whom/which service).

Therapeutic functions

Rehabilitation centres treat the patient and involve his/her environment. They provide specialised therapeutic interventions aiming at various functions: language, speech, communication, (psycho) motor, (meta) cognitive, scholastic skills, social-behavioural, emotional-affective and coping strategies.

Interventions focus on the medical-paramedical and psychosocial treatment. Rehabilitation centres can also deal with technical adjustments and supportive equipment (hearing aid, prosthesis…). They provide information (administrative advice, contacts with external authorities) and refer patients to other professionals if necessary. Aftercare and follow-up of the patient are not mentioned within the conventions.

1.4.3 Specific work practice

Multi-, inter- en transdisciplinary character

Rehabilitation centres are characterised by a multi-, inter- and transdisciplinary organisation. A rehabilitation-team is multidisciplinary (physicians, social workers, psychologists, master in the educational sciences, speech therapists, audiologists, occupational therapists, physiotherapists and psychological assistants).

Physicians must be specialised in psychiatry, neuropsychiatry, (paediatric) neurology, otorhinolaryngology or in paediatrics and in each centre one physician must have the recognition as specialised in rehabilitation. They have the final responsibility for the process of rehabilitation and have to support and supervise the rehabilitation programme. *Psychologists* are therapists who assess, diagnose and treat psychological disorders in children. Mostly they have also a coordinating function: team coordination concerning the content, contacts with other services, support of the family, reporting… *Speech therapists* are therapists who assess, diagnose, treat and help to prevent disorders related to speech, language, reading, spelling, mathematics, cognitive-communication, voice, swallowing and fluency. *Occupational therapists* enable people to do the day-to-day activities despite impairments, activity limitations or participation restrictions.

They also offer help with mathematical problems, writing, visual perception and praxis. *Physiotherapists* treat a range of physical problems resulting from illness, injury or disability. The *psychomotor therapist* usually is an occupational therapist or a physiotherapist (seldom also speech therapist with specialisation) who provides psychomotor therapy to increase motor competence e.g. by improving coordination. They also focus on psychosocial aspects like self-control and planning. A *social worker* informs, guides and support patients and their family throughout the rehabilitation. Often they are also responsible for administrative procedures (for example the management of patient files).

All disciplines are involved in the process of diagnosis, therapy and support of the environment; they work/act together as a team. They work interdisciplinary as they adjust their individual work to that of other team members starting from one point of view and by using an integrated strategy. This way, rehabilitation centres can provide treatment for complex disabilities.

Finally, the rehabilitation activities are also transdisciplinar: knowledge and skills are shared between all the disciplines, so team members work together past the boundaries of disciplines.

Outpatient

Rehabilitation centres strive to keep the patient functioning within his own environment as long as possible. Patients cannot sleep, eat, or stay in the centre outside the hours of therapy. If a certain situation asks more support, interventions can also be extended in a limited way with care in the environment of the patient.

Individualised and based upon needs of the patient and his/her environment

Interventions are based on the needs of the patient and his environment. Work practice for the client and the environment can vary in lengths of sessions, number of participants (individual or group), number and nature of disciplines and place of interventions (inside or outside the centre) within the regulations in their conventions (see Appendix to Chapter 1). Parent interventions can consist of individual support and counselling or group sessions.

Participation of the client and his family

Parents and partners play a very important role in the continuation and implementation of care outside the rehabilitation centre and are highly involved in the rehabilitation process. They can integrate therapeutic activities in the daily routines of the patient and exercise learned skills. Rehabilitation centres expect that this participation is based upon mutual engagement, respect and valuable partnership between the patient and the caregivers.

Professional treatment

Rehabilitation centres are professional and try to work in a scientifically justified way. Due to the lack of specific scientific research, many practices are not evidence based but consensus-based. One of the goals of the conversion plan (see Appendix to Chapter 1) is to develop a protocol concerning evidence-based treatments.

All personnel is qualified and specialised in the target groups they work with. There are frequent opportunities for extra training and specialisation.

Rehabilitation is organized in a systematic way and contains following phases: registration, intake, interdisciplinary diagnostic process, team meetings (also with parents), interdisciplinary interventions, the midterm evaluation and end report closing. One professional coordinates and supervises the whole process for every patient.

Restricted in time

The process of rehabilitation consists of separate consecutive and non consecutive rehabilitation periods, each limited in time. Goals are well-defined and need to be achievable within a short time period. Therapeutic progress is often evaluated and minimum once a year a global evaluation is performed. Therapy will only be prolonged with the approval of the medical adviser from the Sickness Funds (Mutuality).

Based on the development of the care network

Rehabilitation centres work together with the referring specialist and other involved caregivers. Therefore they keep long lasting agreements and co-operations with specialized diagnostic centres, guidance centres, child psychiatric services, teachers, school guidance centres, general practitioners, physicians, university hospitals, patients associations and self-help groups.

1.5 DISTRIBUTION OF NOKPSY REHABILITATION CENTRES AND OTHER (MENTAL) HEALTH CARE IN BELGIUM

1.5.1 Distribution of NOKPSY rehabilitation centres throughout Belgium

In 2008, Belgium has 45 NOK centres and 49 PSY centres. The geographic distribution of the rehabilitation centres is presented in Table 1 and shows quantitative differences between provinces. Most of the NOK and PSY centres are situated in respectively East-Flanders, Liège, West-Flanders and Brussels. Brabant Walloon and Luxembourg have no NOK/PSY centres at all.

Table 1 : Rehabilitation centres NOK and PSY, by province

Region	Province	NOK-centres	PSY-centres	Total
Brussels		7	5	12
Flemish region				
	Antwerp	3	4	7
	Brabant Flemish	3	3	6
	Limburg	3	0	3
	East-Flanders	10	14	24
	West-Flanders	9	3	12
Walloon region				
	Brabant Wallon	0	0	0
	Hainaut	6	3	9
	Liège	4	16	20
	Luxembourg	0	0	0
	Namur	0	1	1
Total		45	49	94

(source: RIZIV, 2008)

The amount of centres does not provide enough information to draw conclusions about the size of the centres, because they differ in capacity. In Table 3 an overview is provided of the maximum lump sums per province. This is combined with the total number of citizens per province (see Table 2) because the population density differs per province. In this way, per province the per capita budget was calculated.

Table 2: Number of citizens per province on the first of January 2007

Region	Province	Number of citizens	Percentage
Brussels		*1.031.215*	*9.74%*
Flemish region		*6.117.440*	*57.80%*
	Antwerp	1.700.570	16.07%
	Brabant Flemish	1.052.467	9.94%
	Limburg	820.272	7.75%
	East-Flanders	1.398.253	13.21%
	West-Flanders	1.145.878	10.83%
Walloon region		*3.435.879*	*32.46%*
	Brabant Wallon	370.460	3.50%
	Hainaut	1.294.844	12.23%
	Liège	1.047.414	9.90%
	Luxembourg	261.178	2.47%
	Namur	461.983	4.36%
Total		10.584.534	100

(source: http://www.statbel.fgov.be)

Again (see Table 3), differences are found between the different provinces: East-Flanders, Liège, West-Flanders and Brussels have the largest capacity per year per capita. Also between the per capita budgets for the regions large differences are perceived. The highest per capita budget is found in the Flemish region, followed by Brussels and the Walloon region. We can also perceive substantial differences between the provinces in one region, for example East-Flanders has a 6.5 times higher per capita budget than Antwerp.

Table 3: Maximum capacity (forfeits/year/capita) of the NOK/PSY rehabilitation centres

Region	Province	NOK-centres	PSY-centres	Total N forfeits	% within Belgium	average N forfeits per year per capita
Brussels		54.203	29.504	83.707	8.19%	0.08
Flemish region		*426.010*	*301.189*	*727.199*	*71.19%*	*0.12*
	Antwerp	22.188	39.711	61.899	6.06%	0.04
	Brabant Flemish	22.780	13.334	36.114	3.54%	0.03
	Limburg	34.020	0	34.020	3.33%	0.04
	East-Flanders	161.028	209.130	370.158	36.24%	0.26
	West-Flanders	185.994	39.014	225.008	22.03%	0.20
Walloon region		*84.043*	*126.557*	*210.600*	*20.62%*	*0.06*
	Brabant Wallon	0	0	0	0%	0.00
	Hainaut	42.262	19.578	61.840	6.05%	0.05
	Liège	41.781	92.015	133.796	13.10%	0.13
	Luxembourg	0	0	0	0%	0
	Namur	0	14.964	14.964	1.46%	0.03
Total		564.256	457.250	1.021.506	100%	0.10

(source: RIZIV, data on April 2008)

In Table 4 an overview is provided of the RIZIV/INAMI expenses for NOK/PSY rehabilitation compared to the total budget for rehabilitation and for medical care

(see Appendix to Chapter 1). The recent proportions of the NOK/PSY-expenses within the total rehabilitation budget is significantly lower than in 1999 (58.202.920€ or 28,54% of the rehabilitation budget) [4].

Table 4: RIZIV expenses for NOK/PSY rehabilitation* and budget for Medical care and total rehabilitation[i]

Year	NOK		PSY		Total		RIZIV medical care	% NOK/PSY	RIZIV rehabilitation	% NOK/PSY
	forfeits	booked expenses	Forfeits	booked expenses	forfeits	booked expenses	budget		budget	
2006	456.484	41.463	335.379	35.660	791.863	77.123	17.735.291	0,43%	347.868	22,17%
2007	457.361	43.278	332.201	37.362	789.562	80.640	18.873.403	0,43%	394.197	20,46%

*Booked expenses and budgets in 1000 euros

Concerning the arbitrary distribution of rehabilitation centres an explanation can be found in the moratorium on the development of new centres. Because the development of rehabilitation centres was left to free initiatives, the distribution of centres resembles the situation before this moratorium. However, the unequal distribution of the Belgian NOK/PSY rehabilitation centres can not solely be attributed to this historical factor. Another explanation, that in a province with less rehabilitation centres, a greater amount of private speech therapists, centres for mental health care, special education, (semi) boarding schools is available, is not sufficient (this is briefly discussed in the following paragraph). Untill now, no other factors were found as possible explanations for this unequal distribution. It is clear that further research is needed.

1.5.2 Distribution of NOKPSY rehabilitation centres compared to other (mental health) care in Belgium

Distribution of private speech therapy, special education, (semi-) boarding schools, centres for mental health care

In Table 5, an overview is provided for the RIZIV/INAMI costs for private speech therapy in 2007 (for nomenclature encodings taken into account, see Appendix to Chapter 1).This table shows that costs for private speech therapy are not higher in the provinces with less rehabilitation centres.

Table 5: the RIZIV/INAMI costs for private speech therapy in 2007

Region	Province	Total €	% within Belgium	€ per capita
Brussels		*2.722.471,54*	*5.24%*	*2.64*
Flemish region		*30.733.084,59*	*59.20%*	*5.02*
	Antwerp	4.716.471,57	9.09%	2.77
	Brabant Flemish	4.261.921,35	8.21%	4.05
	Limburg	3.824.189,95	7.37%	4.66
	East-Flanders	8.354.438,40	16.09%	5.97
	West-Flanders	9.576.063,32	18.45%	8.36
Walloon region		*18.402.546,07*	*35.45%*	*5.36*
	Brabant Wallon	1.660.813,84	3.20%	4.48
	Hainaut	7.182.212,68	13.84%	5.55
	Liège	6.096.711,28	11.74%	5.82
	Luxembourg	1.032.199,72	1.99%	3.95
	Namur	2.430.608,55	4.68%	5.26
-Empty-		*55.218,17*	*0.11%*	*/*
Total		51.913.320,37	100%	4.90

(source: RIZIV, INAMI, data from 2007)

i http://www.riziv.fgov.be/information/nl/statistics/#1

In Table 6, an overview is provided of the number of schools with preschool and primary special education (all types) and with special secondary education. The capacity of these schools is outlined in Table 1.7.

Table 6: Number of schools with preschool + primary special education and schools with special secondary education*

Region	Province	Preschool and primary special education	Special secondary Education	Total
Brussels				
	(Dutch speaking schools)	7	5	12
	(French speaking schools)	34	16 (12*)	50
Flemish region				
	Antwerp	44	30	74
	Brabant Flemish	23	14	37
	Limburg	28	17	45
	East-Flanders	43	26	69
	West-Flanders	45	20	65
Walloon region				
	Brabant Wallon	11	3 (2*)	14
	Hainaut	35	36 (29*)	71
	Liège	26	18 (13*)	44
	Luxembourg	8	7 (5*)	15
	Namur	13	11 (10*)	24
Total				

(source: http://www.ond.vlaanderen.be/onderwijsstatistieken, http://www.statistiques.cfwb.be)
*schools which only organize special secondary education, without organizing preschool and/or primary special educationj

Table 1.7 shows that the region 'Brussels' has the greatest per capita capacity of schools with special education, followed by the Flemish and the Walloon region. According to province, Hainaut, Limburg and West-Flanders have the largest capacity of special education.

* Note: based on data of the school year 2007-2008 for the Flemish region and the Dutch speaking schools in Brussels, based on data of the school year 2006-2007 for the Walloon region and the French speaking schools in Brussels

Table 7: Capacity of schools with preschool + primary special education and schools with special secondary education

Region	Province	Capacity preschool and primary special education	Capacity special secondary education	Total		
				Total	% within Belgium	Average capacity per capita
Brussels		5061	2937	7998	10.32	0.78
	Dutch speaking schools	673	510	1183	1.53	/
	French speaking schools	4388	2427	6815	8.80	/
Flemish region		*28028*	*17679*	*45707*	*58.99*	*0.75*
	Antwerp	7732	4911	12643	16.32	0.74
	Brabant Flemish	3486	1690	5176	6.68	0.49
	Limburg	4654	3246	7900	10.20	0.96
	East-Flanders	6461	3912	10373	13.39	0.74
	West-Flanders	5695	3920	9615	12.41	0.84
Walloon region		*11546*	*12234*	*23780*	*30.69*	*0.69*
	Brabant Wallon	847	435	1282	1.65	0.35
	Hainaut	5398	6882	12280	15.85	0.95
	Liège	3120	2510	5630	7.27	0.54
	Luxembourg	896	931	1827	2.36	0.70
	Namur	1285	1476	2761	3.56	0.60
Total		44635	32850	77485	100	0.73

(source: http://www.ond.vlaanderen.be/onderwijsstatistieken, http://www.statistiques.cfwb.be)

In Table 8, an overview is provided of the number of (semi-) boarding schools linked **to special education in 2007. No information could be obtained concerning the capacity** of the (semi-) boarding schools in the Walloon region and the Dutch speaking Brussels region.

Table 8: Number of boarding schools and semi-boarding schools linked to special education

Region	Province	Boarding school and semi- boarding school	Capacity
Brussels			
	(Dutch speaking)	1	83
	(French speaking)	13	
Flemish region			
	Antwerp	30	2071
	Brabant Flemish	19	1177
	Limburg	20	1291
	East-Flanders	26	2091
	West-Flanders	27	1999
Walloon region			
	Brabant Wallon	7	296
	Hainaut	28	
	Liège	20	
	Luxembourg	10	
	Namur	14	
Total		214	

(source: VAPH, data from 31 December 2007, *http://www.enseignement.be/citoyens/annuaires/spe/liste3.asp* AWIPH)

In Table 9 and Table 10 an overview is provided of the number of centres for mental health care (CGGZ) and their capacity in 2007 in Flanders.

Table 9: Centres for mental health (CGGZ) per province in 2007

Region	Province	Number
Brussels		1
Flemish region		
	Antwerp	5
	Brabant Flemish	3
	Limburg	3
	East-Flanders	5
	West-Flanders	4
Total		

(source: Vlaams Agentschap Zorg en Gezondheid, data from 2007)

Table 10: The cost of centres for mental health (CGGZ) in 2007

Region	Province	Costs	% within Belgium	€ per capita
Brussels		3.716.520,61		*3.60*
Flemish region		*43.045.906,71*		*7.04*
	Antwerp	11.957.071,22		7.03
	Brabant Flemish	6.356.775,15		6.04
	Limburg	6.445.308,39		7.86
	East-Flanders	10.636.660,55		7.61
	West-Flanders	7.650.091,40		6.68
Total				

(source: Vlaams Agentschap Zorg en Gezondheid, data from 2007)

1.5.3 Conclusion: NOKPSY rehabilitation capacity versus capacity of other care forms per capita per province

In Table 11, a comparison is provided between the per capita capacity for NOK/PSY in the province, the costs for private speech therapy per citizen, the capacity for special education per citizen and the costs in EUR for centres for mental health care per citizen.

Table 11: Comparison: Forfeit NOK/PSY citizen in the province, costs in € for private speech therapy/citizen in the province, capacity of special education/citizen in the province and costs in € for centres for mental health/citizen in the province

Region	Province	average N forfeits of NOK/PSY per capita	average RIZIV/INAMI cost for speech therapy per capita (€)	average capacity of special education per capita	average budget of centres mental health per capita
Brussels		0.08	*2.64*	0.78	*3.60*
Flemish region		*0.12*	*5.02*	*0.75*	*7.04*
	Antwerp	0.04	2.77	0.74	7.03
	Brabant Flemish	0.03	4.05	0.49	6.04
	Limburg	0.04	4.66	0.96	7.86
	East-Flanders	0.26	5.97	0.74	7.61
	West-Flanders	0.20	8.36	0.84	6.68
Walloon region		*0.06*	*5.36*	*0.69*	/
	Brabant Wallon	0.00	4.48	0.35	/
	Hainaut	0.05	5.55	0.95	/
	Liège	0.13	5.82	0.54	/
	Luxembourg	0	3.95	0.70	/
	Namur	0.03	5.26	0.60	/
Total		0.10	4.90	0.73	

The assumption that there is a greater amount of other kind of services in regions with less NOK/PSY rehabilitation centres seems not to be valid.

However, no complete conclusions can be drawn as other care providers for the involved target groups were not included. Statistics of day and night rehabilitation centres, child psychiatrists, paediatricians… were not incorporated because most of these known budgets do not reckon with diversity of disorders, age groups, kind of treatments… Services of the Department of Education (special support of teachers for children with learning disorders) are also not discussed since for this population, the number of children in need of multidisciplinary therapy (instead of e.g. mono-disciplinary therapy) is not known. Also, even for the included providers, the actual number of patients that potentially could have been treated by NOK/PSY centres is not known. Therefore a full comparison with the capacity of NOK/PSY rehabilitation centres is not possible.

1.5.4 Evolution in organisation of the Belgian rehabilitation centres

1.5.4.1 In general

Besides an adjustment in 1997 to the regulations about group therapy and some adaptations in the estimation of the maximal capacity per centre, the RIZIV/INAMI conventions and rehabilitation centres did not change since 1996. Meanwhile, changes occurred in the field of treatment and care. These presumably have a twofold origin: the growing specialisation within the sector and the influences of the external society (for example more involvement of patients with disabilities in the social debate).

All of this resulted in a debate on the goals, meaning and definition of rehabilitation. The work group "Philosophy and definition of the rehabilitation sector" created by the College van geneesheren-directeurs/Collège de Médecins -Directeurs (College of medical directors) and the Raad voor advies inzake revalidatie/ Conseil consultatif de la rééducation fonctionnelle (Council for advice on rehabilitation; see further) defines the common characteristics of the rehabilitation this way:

1. Treatment of the consequences of a disease/disorder and the restrictions in activities due to this disease/disorder.
2. Helping to reduce all (psychological, socio-economical and physical) consequences of the functional disorders.
3. Insuring a holistic approach of the patient that helps him in his natural environment.
4. The complexity of functions within the rehabilitation programs requires the coordination of multidisciplinary teams. Multidisciplinary work is essential, but consultation between disciplines is of crucial importance.
5. The mutual goal of rehabilitation is its contribution to guide the patient in conquering obstacles, adapting and building a future to reach an optimal quality of life.

Rehabilitation cannot succeed without the cooperation of the patient and his environment (College van geneesheren-directeurs; Raad voor Advies inzake Revalidatie, 2004).

These characteristics fit within the definition of rehabilitation that is provided by the WHO: "Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools, they need, to attain independence and self-determination"[k].

1.5.4.2 More in detail

Recommendations from the council for advice on rehabilitation

Under the authority of the RIZIV/INAMI, the College of medical directors (College van geneesheren-directeurs/Collège de Médecins Directeurs) and the Council for advice on rehabilitation (Raad voor advies inzake revalidatie/ Conseil consultatif de la rééducation fonctionnelle) evaluated the work practice of rehabilitation centres and formulated desired changes [6]. Therefore, they created 7 working groups, each one corresponding with a certain domain of the rehabilitation sector: loco-motor and neurological rehabilitation, cardiac rehabilitation, respiratory rehabilitation, rehabilitation of speech and hearing disabilities, psychological rehabilitation, rehabilitation for mental disabilities and finally a working group for the philosophy and the definition of rehabilitation. The aim of these working groups is to map the functional and social rehabilitation sector based upon improved standards. The reports and recommendations of the working groups can be consulted in detail in the report 'Verslag over de stand van de revalidatiegeneeskunde in België'.[6] The most important conclusions within this scope are:

- The medical rehabilitation specialist should play a central role
- ICD-10 and ICF should be the basis for the rehabilitation program
- Multidisciplinarity and networking are crucial elements in rehabilitation.
- The financing of the rehabilitation centres should take these crucial characteristics into account (multidisciplinary composition of the team; and team- or network consultations)
- Especially for child rehabilitation, the specific character of the centres should be further clarified
- An equal regional distribution of the centres should be developed, starting from a clear planning
- The gaps and differences between the federal government and the communities and regions hinder a good management of the rehabilitation programs, harmonising is necessary

In another report, specific propositions and conclusions were made concerning the rehabilitation of children [7] (Ministerial working group concerning the mental healthcare for children)).

k (http://www.who.int)

For the NOK/PSY rehabilitation centres it was concluded that until now, they are too little liaised to the rest of the mental health care system for children and adolescents.

Also, it remains unclear what could be the specific position of these centres amidst the other caregivers for the same target groups, and which specific domains they are specialised in as compared to the other participants in the care field.(e.g. specific working methods, etc.). According to the WHO guidelines, rehabilitation can be subdivided in three types: acute rehabilitation, rehabilitation of complex and persistent functional disorders with a high incidence and rehabilitation of complex, severe consequences with a low incidence that need a specific knowledge and infrastructure. The NOK/PSY sector is then perceived as rehabilitation of the second type.

Until today, these analyses and propositions are still under discussion and no practical applications and regulations exists.

The conversion project

Secondary to changes in the field of rehabilitation and changes in the (health) care system in general, it was felt that some adaptations to the organisation and functioning of the NOK/PSY centres were necessary. To formulate recommendations on which changes to introduce, the conversion project has been set up. So far, the NOK/PSY rehabilitation centres agreed on a consensus note of the conversion project, involving a description of desired changes concerning the target groups and the working modalities. Some specific topics in the consensus note are still preliminary, and need further discussion.

Target groups

In the future, some target groups would be common to all NOK/PSY centres, whereas other target groups would only be treated in centres specifically applying for it. The conversion project describes its advice for the common target groups. For the specific target groups (e.g. conductive and sensorineural hearing loss), the conversion project did not offer advice yet. Recently proposals were made concerning hearing disorders, stuttering, cerebral palsy and brain damage.

The target groups described in the conversion project are mainly based on ICD-10 and ICF and concern developmental disorders (e.g. pervasive developmental disorders, developmental disorders of language and speech). For more details, see Appendix to Chapter 1.

Working Modalities

The description of desired working modalities in the consensus note is a reaction towards the actual regulations of the conventions. The following key points of the changes in working modalities can be distinguished: strengthen the diagnostic function, make duration of the therapy more flexible, mark out the multidisciplinary work, reimburse extra muros activities with others than child or parents; adjust the composition of the team. For more details, see Appendix to Chapter 1.

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When all discussions will be finalized, the 'College van Geneesheren-directeurs' has to discuss and eventually accept the full consensus note. In the meanwhile, an adjustment is expected in 2009 in rehabilitation centres with no or little logistic personnel (employee, receptionist, handyman …). The need for more psychosocial personnel is directly linked to the whole conversion project (target groups and working modalities).

Key points

- **In 1963 the 'Rijksfonds voor Sociale Reclassering van Minder-Validen/le 'Fonds national de reclassement social des handicapés' was established to regulate and finance all aspects of the rehabilitation facilities in Belgium. In 1991 this became the responsibility of the RIZIV/INAMI (federal level) and the VAPH/AWIPH (level of communities).**
- **The centres receive most of their incomes from the department of health care. In 2007, the RIZIV/INAMI expenses for NOK/PSY rehabilitation amounted to 80 mil Euro, i.e. 0.43% of the total RIZIV/INAMI expenses and 20% of the RIZIV/INAMI rehabilitation expenses.**
- **Since 1996 the work practice of the rehabilitation centres are set out in the RIZIV/INAMI-conventions separately for NOK and PSY rehabilitation centres.**
- **In 2008, most of the 45 NOK and 49 PSY centres are situated in respectively East-Flanders, Liège, West-Flanders and Brussels; whereas Brabant Wallon and Luxembourg have no NOK/PSY centres. The same provinces have also the largest per capita capacity.**
- **When looking at the per capita capacity for the regions in Belgium, great differences are perceived: the greatest per capita budget is found in the Flemish region, followed by Brussels and the smallest per capita budget is in the Walloon region. These differences can be linked at the moratorium concerning the financing of new centres since 1987.**
- **The assumption that there is a greater amount of other kind of services (private speech therapists, special education…) in regions with less rehabilitation centres seems not to be valid. However, no complete conclusions can be drawn, since it is not possible to quantify the role of some caregivers for the NOK/PSY targets groups (e.g. child psychiatrists, special help at school…).**
- **In the nearby future, the Belgian rehabilitation sector and also the NOK/PSY centres will be submitted to adjustments and changes. Recommendations from the council for advice on rehabilitation and recommendations from the sector (the conversion project) have already been formulated.**
- **Recommendations from the council concern the main characteristics of rehabilitation and the needs for change in planning and organisation, e.g. a model containing three types of rehabilitation centres. Recommendations in the "conversion project" concern the target groups and the working modalities (strengthen the diagnostic function, make duration of the therapy more flexible, mark out the multidisciplinary work, reimburse extra muros activities with others than child or parents; adjust the composition of the team).**

1.6 CONCLUDING REMARKS

1.6.1 Aspects of national NOK/PSY rehabilitation organisation

1.6.1.1 Regional distribution

One of the main conclusions from Chapter 1 is, that the NOK/PSY rehabilitation centres as well as the yearly per capita NOKPSY budget are spread unequally throughout Belgium. This is not only true on the level of the regions, but also on the level of the provinces within one region. E.g. the per capita budget is largest in Flanders, followed by Brussels, whereas the per capita budget in Walloon is only half the Flemish budget.

The assumption that there is a greater amount of other types of services (private speech therapists, special education with or without (semi-) boarding school, centres for mental health) in regions with less rehabilitation centres seems not to be valid. However, no complete conclusions can be drawn as the contribution of some other care providers for the involved target groups could not be included (child psychiatrists, educational support in mainstream schools…). Apart from a historical explanation, other explanations can theoretically be found for this unequal distribution but they are difficult to prove.

A plea for a more equal regional distribution of the centres, starting from a clearly outlined planning, has already been formulated by the RIZIV/INAMI College of medical directors (College van geneesheren-directeurs/Collège de Médecins Directeurs) and the Council for advice on rehabilitation (Raad voor advies inzake revalidatie/ Conseil consultatif de la rééducation fonctionnelle)[6].

Although many NOK/PSY rehabilitation centres informally work together with other caregivers in the field, no clear definition has been found during this study on the specific task rehabilitation centres have as compared to other care providers belonging to their network. Also, some other network services belong to other governmental departments or are financed on the regional and not the federal level. This clearly will complicate an efficient planning of service needs.

1.6.2 National budget

The budget for the NOK/PSY centres slightly declined as compared to the total RIZIV/INAMI budget, namely from 0.48% in 1999 to 0.43% in 2007.

As compared to the total RIZIV/INAMI rehabilitation budget, NOK/PSY centres went down from more than 30% (1997-1998) and 28.5% (1999) to 20.5% in 2007.

2 DATA ANALYSES

2.1 VALIDATION OF DATA

2.1.1 Introduction

Patients within the rehabilitation centres in Belgium are registered following the conventions "PSY-NOK" with the RIZIV/INAMI. This procedure fails to provide a full description of the population: it refers to the 'International Classification of Diseases and Related Health Problems 10th revision' [ICD-10] (World Health Organisation [WHO], 1992) but there are also differences and it does not contain a registration of co-morbidity of the disorders. This way the data about the treated disorders are limited and potentially lead to misinterpretation of the available information. So communication between sectors or international communication about target groups as well as comparison of these groups is difficult. Taking these problems in consideration, the rehabilitation sector initiated in 2005 a trial using registration of patients using ICD-10.

'The ICD-10 has become the international standard diagnostic classification for all general epidemiological and many health management purposes. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to other variables such as the characteristics and circumstances of the individuals affected, reimbursement, resource allocation, quality and guidelines.'[1] The ICD-10 was chosen instead of the 'Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision' [DSM-IV-TR] (American Psychiatric Association [APA], 2000) because the DSM-IV-TR does not allow to register other than psychological disorders. Like all categorical classification systems, ICD-10 implies a reduction of reality but using ICD-10 holds a link to the future where the International Classification of Functioning, Disability and Health [ICF] (WHO, 2001) will make its introduction. Where ICD-10 is useful for the labelling of disorders, ICF is used to define the impact of these disorders on daily activities and personal functioning in society. This should be the main consideration before starting rehabilitation and ICF provides the clinician a standardized instrument for doing so. However, ICF is still a theoretical framework that needs operationalisation. As such, the registration under study was based on ICD-10 only, which was sufficient for the aim of the trial and of this study. The mean purposes of the project was to create a transparent and consistent view on the patient population, make communication and research in a uniform language possible and monitor evolutions, similarities within and differences between the population in the rehabilitation centres and those treated by other caregivers.

2.1.2 Procedure

The registration of ICD-10 codes was initialized by the 'Federatie van Centra voor Ambulante Revalidatie'/ Fédération des Centres de Réadaption Ambulatoire' (2005). From the 94 NOK and PSY rehabilitation centres in Belgium, 90 centres are members of this federation (26 Flemish NOK centres, 24 Flemish PSY centres, 15 Walloon NOK centres and 25 Walloon PSY centres). All these members were invited to participate and 60% (n=54) of the centres accepted. This is 63% (n=26) of all NOK-centres and 57% (n=28) of all PSY-centres who are members of the federation. PSY and NOK centres are not equally distributed in Belgium. The distribution of Flemish/Walloon NOK-centres is 1.7/1 and the distribution of Flemish/Walloon PSY-centres is 1/1. Thanks to the cooperation of 54 rehabilitation centres, data of 4907 patients could be sampled. This is almost half of the total yearly population in NOK and PSY-centres, which are approximately 9900 patients (Study RIZIV/INAMI. Leefbaarheid en kwaliteit van de 'NOK' en 'PSY', inrichtingen in het raam van de overeenkomsten afgesloten met het RIZIV. Maart 2003).

1 http://www.who.int

All involved rehabilitation centres received their documentation about the study in January 2005. During a trial period in the Dutch speaking centres from February 2005 until June 2005, the centres had the opportunity to report problems concerning software and practical problems with the classification to a helpdesk. Most of the centres used specific software like 'Amfora' to register all their information about their patients in one database. This software was adapted to the registration of client characteristics, using the ICD-10. Centres that were not familiar with this system received a training and extra support. In March 2005, the 'Federatie van Centra voor Ambulante Revalidatie' organized a training and an evaluation session for the physicians and psychologists responsible for the ICD-10 registration. For the French rehabilitation centres, a trial of the registration project was done between the first of January and the end of June 2005. The proposition was made for all participating French speaking centres to join a working group the 26 of May 2005 for analyses and discussions concerning this trial registration project. The French speaking centres registered in an Excel file in order to make it easier to analyse/transform the findings afterwards. The registered variables for both the Dutch and French speaking rehabilitation centres are provided in Appendix to Chapter 2.

During the trial, new patients and patients who were at that moment already following therapy were independently classified by the medical doctor and by one or more other members of the team. To develop an internal, uniform and consistent application of the ICD-10 classification, encodings were compared and discussed. Codes could be changed over time. The official registration started on July 1st, 2005 and the data were collected from January 1st, 2006 until the end of June 2006 for the Dutch speaking rehabilitation centres. The effective registration for the French speaking centres started from the first of October 2005 for the duration of one year. In November 2005 the participating French speaking centres could participate in a meeting to exchange experiences and make discussion/questions possible. This registration involved all new patients as well as patients who continued therapy. From all patients or their parents, an informed consent was obtained to use the data for scientific purposes. If parents were not willing to give this information, data were excluded. The collected data were sent to Sig, an institution that works together with the rehabilitation centres and other caregivers, special education etc. for research and training[m]. To check the representativeness of the sent data the total number of patients in therapy at the time of data collection was given also. All processing of data was done anonymously.

2.1.3 Cleaning of the data – input validation

In Appendix to Chapter 2 an overview of registered variables is provided, showing the difference in the amount of collected variables between Dutch and French speaking rehabilitation centres.

Initially it was necessary to clean the database to make a validation of the data and statistical analysis possible. A detailed description of the actual cleaning of the data is provided in Appendix 3 to Chapter 2. Most of the cleaning was made according to a document with frequently asked questions formulated by rehabilitation centres in October 2005 (see Appendix 1 to chapter 2 for "Frequently asked questions").

E.g., errors were changed (non existing codes or out of range codes) in '888' to make a distinction between missing values and errors. Further details on the cleaning process can be found in Appendix 3 to chapter 2.

2.1.4 Post hoc random sample verification

Although it is unusual to perform a post hoc random sample verification in research, one was executed in order to judge the validity and reliability of the data. There are no statistic rules for this procedure, but based on the obtained percentage of errors, an estimation is desired in order to know whether the whole data matrix is valid and if accurate conclusions can be drawn. This validation aimed at verifying if the registration of variables was performed as agreed.

m www. sig-net.be

It should be noted that this large data registration had been performed by team members of the different rehabilitation centres, and not by one single person.

However, because a registration trial period had been completed, a helpdesk was available and training sessions had been organized, it was presumed that agreement between several encoders was acceptable. Hence, the validation did not include an independent encoding of a random sample of patients by the researchers (e.g. based on the patient notes), followed by verification if these encodings corresponded indeed with the encodings registered by the rehabilitation team. Thus, this post hoc random sample verification gives us an idea of the accuracy of the input of data.

The registration data of all rehabilitation centres were put together in one database. A random sample of 41 record numbers was drawn from that database. This is nearly 1% of the total record numbers. Of the 41 record numbers, 31 different rehabilitation centres could be distinguished. These rehabilitation centres were contacted and informed about the purpose of this validation. By using the patient number or date of birth, information was gathered of the selected patient. By doing so, the anonymous processing of data was guaranteed. The gathered information by telephone was registered by two independent researchers to reduce the risk of mistakes. The information provided by telephone was compared with the information in the database. Based upon the majority of registered variables (except 'type of disciplines', 'ICD-10 codes' and 'registration date of ICD-10 codes'), an acceptable error rate of 0.5% for the Flemish and 0.8% for the Walloon rehabilitation centres was found. The overall error rate was 0.6%. Due to changes in the course of a rehabilitation programme, it was sometimes difficult for the rehabilitation centre to retrieve the initial information of variables such as 'type of disciplines', 'ICD-10 codes' and 'registration date of ICD-10 codes'. However, it can be noticed that the information provided through the telephone was in line with the information available in the database. This is the reason why these variables were not included in the calculation of the overall error rate. During this post hoc random sample verification, one rehabilitation centre that was included twice and one patient who was registered twice, was discovered. These mistakes were adjusted. In addition, there emerged a problem with the variable 'PSY-NOK'. Some of these labels of the centres were wrong (NOK centres called PSY and vice-versa) and therefore corrected according to the official label of the centre. Finally, two 'non-existing' patients were also detected and were removed from the database. This may have been the result of a wrong input in date of birth or patient number.

2.1.5 Conclusion

How data were collected has an important impact on the validity of the data. In this conclusion strengths and weaknesses of this data collection are discussed. The use of a universal and well-defined classification system, a large sample size, a trial period, a training and evaluation session, a helpdesk, compared and discussed encodings… all contribute to the strength of this registration. However, the weaknesses of this process need also be considered. The decision to register patients in rehabilitation centres by multiple caregivers using ICD-10, made this research more vulnerable for subjectivity. A more uniform registration can be obtained when only one specialist for the registration is involved in all rehabilitation centres. Because of the size of this research this was not feasible. A second weakness was the possibility of wrong input. Some of the centres did not use the exclusion criteria of the ICD-10. By cleaning the data the researchers tried to retrieve the correct codes. Finally, there was a difference in the amount of collected variables between Dutch speaking and French speaking rehabilitation centres. As a result, some of the analyses must be done separately for each region.

The next analyses contain a description of the characteristics of Belgian rehabilitation centres and the characteristics of patients in rehabilitation centres. The way of data collecting has its implications on the data analyses. Data were analysed using SPSS (Version 15).

2.2 CHARACTERISTICS OF THE REHABILITATION CENTRES IN THE SAMPLE

2.2.1 Participating rehabilitation centres

2.2.1.1 Participating rehabilitation centres by number

From the 94 NOK and PSY rehabilitation centres in Belgium, 90 centres (26 Dutch speaking NOK centres, 24 Dutch speaking PSY centres, 15 French speaking NOK centres and 25 French speaking PSY centres) are members of the 'Federatie van Centra voor Ambulante Revalidatie'/'Fédération des Centres de Réadaption Ambulatoire'. All these members were invited to participate and 60% (n=54) of the centres accepted to cooperate with this project. In detail, 63% (n=26) of all NOK centres and 57% (n=28) of all PSY centres in the 'Federatie van Centra voor Ambulante Revalidatie'/'Fédération des Centres de Réadaption Ambulatoire' were included.

2.2.1.2 Participating rehabilitation centres by capacity

In the sample 3658 patients are treated in Dutch speaking NOK and PSY rehabilitation centres (thus in the Flemish region) and 1249 patients are treated in French speaking NOK and PSY rehabilitation centres (see Table 2). To prove the representativeness of the sample it is necessary to take into account the percentage of the maximum capacity provided for each region (Brussels, Flemish region and Walloons region). In Table xx in Chapter xx, it can be perceived that 8.19% of the maximum capacity in Belgium is in Brussels, 71.19% in the Flemish region and 20.9% in the Walloon region. In our sample the rehabilitation centres in the region Brussels are all French speaking centres, so we add the Walloon region to the percentage of Brussels. To obtain a perfect representative sample, 3493 patients should have been registered in Dutch speaking centres and 1414 patients should have been registered in French speaking centres.

The 8.19% of the maximum capacity in Belgium, going to Brussels can be divided in 5.30% in NOK centres and 2.98% in PSY centres. The 20.9% of the maximum capacity in Belgium, going to the Walloon region, can be divided in 8.23% in NOK centres and 12.39% in PSY centres. In our sample, the rehabilitation centres in the region Brussels, are all French speaking so we can add the percentage of Brussels NOK with Walloon NOK centres (13.53%) and we can add the Brussels PSY centres to the Walloon PSY centres (15.28%). This means that in theory 664 patients must be selected from French NOK centres and 750 patients must be selected from French PSY centres. In the sample there were respectively 377 patients and 872 patients.

The 71.19% of the maximum capacity in Belgium, going to the Flemish region can be divided in 41.70% in NOK centres and 29.49% in PSY centres. This means that in theory 2046 patients must be selected from Dutch NOK centres and 1447 patients must be selected from Dutch PSY centres. In the sample there were respectively 2145 patients and 1513 patients. These findings show a reasonable representativeness of the sample, with the remark that there were too little participating patients in French NOK centres.

However, it should be kept in mind that the total capacity for the Flemish region (71.19%) is higher as compared to the total capacity for the Walloon region (20.9%), when taking into account the amount of inhabitants in Flanders respectively Walloon (see Table 1.3 in Chapter 1). This further adds to the fact that the total number of patients participating for the Walloon region is rather low and possibly not large enough to allow for firm conclusions, especially when subgroups are considered (see further analyses). Data concerning the French speaking or Walloon centres should be treated with caution, especially for the NOK centres.

2.2.2 Location and official language

2.2.2.1 Location and official langue by number

Table 12 provides an overview of the NOK and PSY centres that participated, subdivided by province. In this table and in further analyses, the term 'Brabant' stands for all rehabilitation centres situated in Flemish Brabant, Walloon Brabant and Brussels.

By using 'Brabant' we can guaranty the anonymity of statistic results[n]. Most of the rehabilitation centres in the sample are localised in the region of Flanders and have Dutch as official language (19/26 NOK centres and 12/28 PSY centres), this is 57% of the rehabilitation centres in the sample. Twenty (7/26 NOK and 16/28 PSY) rehabilitation centres are Walloon/Brussels, having French as official language. All rehabilitation centres situated in Brussels have French as official tongue. Consequently, 31 Dutch and 23 French speaking rehabilitation centres participated.

The distribution of 12 Dutch speaking PSY centres and 16 French speaking PSY centres (1/1.3) in the sample is quite equal to the distribution of the total number of existing PSY centres, since the ratio Dutch/French speaking PSY-centres is 1/1. The distribution of Dutch/French speaking NOK-centres is 1.7/1; this is less equal to the distribution in the sample, namely 19 Dutch speaking NOK centres and 7 French speaking NOK centres (2.7/1).

In Table 13, an overview of the total Belgian NOK/PSY centres and participating centres is provided, divided by NOK/PSY and language spoken in the centre. Due tot privacy rules it was impossible to provide information concerning the maximum capacity of each participating centre. Therefore, the distribution of the participating patients, without making the distinction for language and NOK/PSY is presented beneath.

Table 12: Participating NOK and PSY centres, by province

Province	NOK	PSY	Participating patients NOK/PSY
Antwerp	1	0	93
Brabant	3	2	355
West-Flanders	7	3	1020
East-Flanders	9	8	2249
Hainaut	2	2	175
Liège	3	12	774
Limburg	1	0	179
Namur	0	1	62
Total	26	28	4907

n This is done because certain provinces in Brabant are only represented by 1 centre with a certain language and therefore the anonymity of data can not be guaranteed

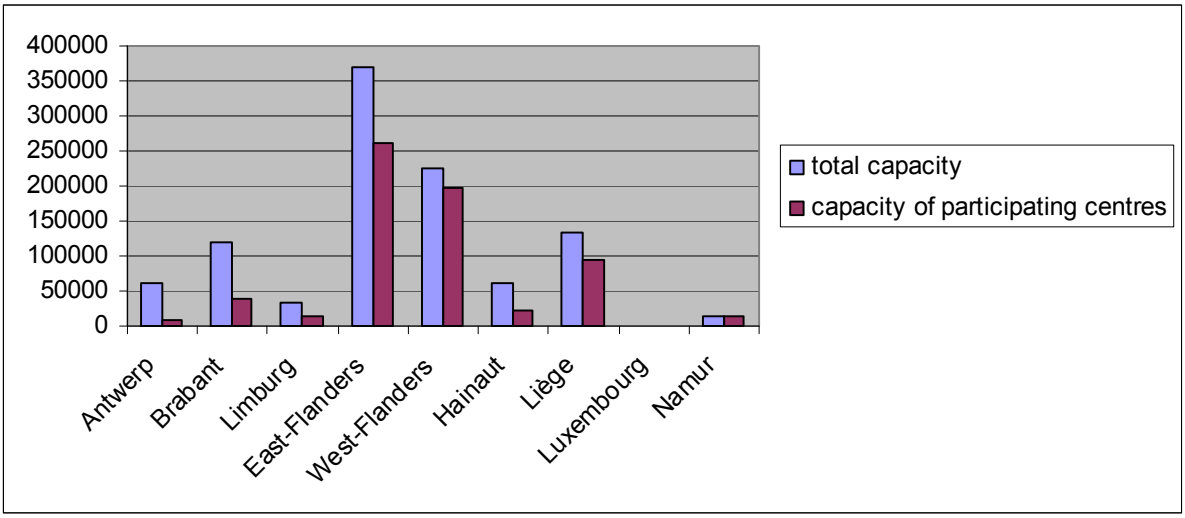
Table 13 Total Belgian NOK/PSY centres and participating centres, divided by NOK/PSY and language spoken in the centre

Total Belgian NOK/PSY centres	Total Belgian centres NOK and PSY	Total centres Member of Federation	Total Federation centres; Number NOK and PSY	Total Federation centres; Number Dutch and French	Federation Centres Participating in the study	Federation Centres Participating in the study; (Number of patients in Dutch and French speaking centres)	Federation Centres Participating in the study; Number NOK and PSY (Number patients)	Federation Centres Participating in the study; Number Flemish, Brussels, Walloon centres	Number of Dutch and French participating patients
94	45 NOK (47.9%)	90 (95.7%)	41 NOK (45.5%)	26 Dutch (63.4%)	54 (60%)	4907 patients (3658 Dutch, 1249 French)	26 NOK (48.1%) (2522 patients)	19 Flemish (73.1%)	2145 patients (Dutch) (85.1%)
				15 French (36.6%)				2 Brussels (French) (7.7%)	377 patients (French) (14.9%)
	49 PSY (52.1%)		49 PSY (54.4%)	24 Dutch (49%)				5 Walloon (19.2%)	
				25 French (51%)			28 PSY (51.8%) (2385 patients)	12 Flemish (42.8%)	1513 patients (Dutch) (63.4%)
								1 Brussels (French) (3.6%)	872 patients (French) (36.6%)
								15 Walloon (53.6%)	

2.2.2.2 *Location and official langue by capacity*

In Figure 1, a comparison is made between the total realisable maximum capacity[o] of the NOK and PSY rehabilitation centres in Belgium per province, with the realisable maximum capacity of the participating centres in this study (see Chapter 1). A remarkable difference in participation grade is noticed. For example, Namur has the highest participation grade (100%) whereas Antwerp has the lowest (14.3%). The participation grade for Brabant, Limburg and Hainaut is about 35% and the participation grade of East- and West Flanders and Liege is between 70 and 87%. Research history of these centres, less publicity of the research project, high pressure of work or less interest in this project are possible explanations for this distortion.

Figure 1: Comparison total maximum capacity with maximum capacity of participating centres



* 0-400000 is the maximum realisable capacity

Participation of both Dutch and French speaking rehabilitation centres are similar. The participation grade of Dutch speaking rehabilitation centres is 62% and the participation grade of French speaking rehabilitation centres is 64%.

o See RIZIV/INAMI NOK/PSY Conventions article 29 § 1

Key points

- **To obtain information about the population within the Belgian NOK and PSY rehabilitation centres, the 'Federatie van Centra voor Ambulante Revalidatie'/'Féderation des Centres de Réadaption ambulatoires' (2005) initialised a registration procedure using ICD-10. Of the members of this federation 54 (26 NOK and 28 PSY, 31 Dutch speaking centres and 23 French speaking centres) centres (57% of all Belgian NOK/PSY centres) cooperated and data of 4907 patients (3658 patients in Dutch speaking centres and 1249 patients in French speaking centres) could be sampled. Cleaning of the provided data and a post hoc random sample verification were performed in order to provide valid information**
- **A remarkable difference in participation grade is noticed within regions (Namur> East- and West Flanders and Liege > Brabant, Limburg and Hainaut> Antwerp). No differences were perceived between the participation grade (i.e. the relative number of participating centres) of Dutch and French speaking rehabilitation centres**
- **Taking the maximum capacity in Dutch speaking and French speaking NOK/PSY rehabilitation centres and the amount of inhabitants into account, the sample proved to be quite representative, with the consideration that for the French centres (especially the French NOK centres) the number of participating patients is somewhat lower than for the Dutch speaking centres. Therefore analyses and conclusions should be treated with care.**

2.3 CHARACTERISTICS OF THE PATIENTS IN REHABILITATION CENTRES IN THE SAMPLE

2.3.1 Age and sex

The sample comprised 4907 patients (2385 from PSY centres and 2522 from NOK centres) with an age range of 1 to 80 years (mean 9 years 10 months, SD 2 years 9 months). The most prevalent age group contains the children between 7 and 9 years (51.29%) and 85.93% is between 4 and 12 years, this is in agreement with the expectations (e.g. Leefbaarheidsstudie RIZIV 2003: successively 41.16% and 88.01%).

The figures in Appendix 8 to chapter 2 provide more information concerning the age range within the six main index disorders, showing that younger children are attending rehabilitation centres, when 'Mild mental retardation' or 'Conductive and sensorineural hearing loss' are the main index disorders. For 'Conductive and sensorineural hearing loss', also older children and adults are present in the rehabilitation centres (this category contains both the congenital disorders, as well as the acquired disorders).

The male/female ratio in the sample is 1.9/1. This is according to the general knowledge that boys have a higher risk for developing behavioural and developmental disorders, compared to girls. Descriptive information for the sample is presented in Table 14 (according to educational level). More details on number of participants per year of age in the data sample as well as on the male/female ratio for all ages and within each of the 6 main index disorders, can be found in the Appendix 7 to chapter 2. In all main index disorders a male preponderance is found.

Table 14: Age in sample (Dutch and French) according to sex

	Female			Male			Total	
Age	N	% within sex	% within age	N	% within sex	% within age	N	%
1-2	17	41.46	1.01	24	58.54	0.74	41	0.84
3-5	113	30.46	6.71	258	69.54	8.00	371	7.56
6-11	1166	33.28	69.28	2338	66.72	72.52	3504	71.41
12-17	324	37.28	19.2	545	62.72	16.91	869	17.71
>18*	63	51.64	3.74	59	48.36	1.83	122	2.49
Total	1683	34.30	100	3224	65.70	100	4907	100

* this age group was also included in the further analyses

2.3.2 Country, province and official language

From the 4907 patients, respectively 3658, 1008 and 241 patients were treated in rehabilitation centres situated in Flanders, Walloon and Brussels. In this particular case, all rehabilitation centres situated in Brussels have French as official language, consequently 3658 patients were in Dutch rehabilitation centres and 1249 patients were in French speaking rehabilitation centres. This remark is very important for the representativeness of the further analyses, because the Dutch speaking rehabilitation centres collected more variables for statistic analysis than the French speaking rehabilitation centres (see 'cleaning of the data – input validation).

'Country' and 'province' of residence were only registered by the Dutch speaking rehabilitation centres (see Appendix 2 to Chapter 2 which outlines the registered variables in the Dutch and French speaking rehabilitation centres). All patients except four, or 99.9% of the participants, live in Belgium. In Table 15 an overview of the living places of the patients in the Dutch rehabilitation centres is presented. As abovementioned, 'Brabant' contains all rehabilitation centres situated in Flemish Brabant, Walloon Brabant and Brussels.

In this table, 8 patients living in Walloon provinces are registered in Dutch speaking rehabilitation centres. Probably these children live in Wallonia at the border to Flanders and are Dutch speaking.

The opposite line of reasoning is impossible due to lack of registration information from the living places of patients in French rehabilitation centres.

Table 15: Living places of the patients in Dutch rehabilitation centres

Province	N	%
Antwerp	135	3.69
Brabant	126	3.45
West-Flanders	1086	29.71
East-Flanders	2123	58.08
Hainaut	6	0.16
Liège	2	0.05
Limburg	177	4.84
Total	3655	100
Missing cases	3	

2.3.3 Educational level

'Educational level' was only registered by the Dutch rehabilitation centres (see Appendix 2 to Chapter 2 which outlines the registered variables in the Dutch and French speaking rehabilitation centres). Most of the patients are going to primary education (51.29%) and preschool (26.54%). From the patients who are going to school,

16.05% are in special education. Descriptive information for the sample is presented in Table 16.

It is remarkable that 26.5% of the children are in preschool and only 7.5% are between 3 and 5 years old.

More details on the educational level within each of the 6 main index disorders, can be found in the Appendix 7 to chapter 2.

Table 16: Educational level of patients in Dutch rehabilitation centres

Educational level	N	%
Not going to school	121	3.40
Preschool	945	26.54
Preschool, special education	63	1.77
Primary education	1826	51.29
Special primary education	460	12.92
Secondary education	46	1.29
Special secondary education	29	0.81
Professional training	1	0.03
University	1	0.03
General secondary education	21	0.59
Technical education	31	0.87
Technical and vocational training	16	0.45
Total	3560	100
Missing cases	98	

Key point

- **The largest age group is 6 to 11 years (71.44%) and toddlers account for 8.38% of the sample**
- **At the age of seven when children start to go to primary education, the prevalence in rehabilitation centres is rising. Younger children are attending rehabilitation centres, when 'Mild mental retardation' or 'Conductive and sensorineural hearing loss' are the main index disorders. For 'Conductive and sensorineural hearing loss', also older children and adults are present in the rehabilitation centres (this category contains both the congenital disorders, as well as the acquired disorders).**
- **The male/female ratio in the sample is 1.9/1 and is stable across the index disorders**
- **About 16% of the children treated in NOK/PSY rehabilitation centres are in special education. About 79% is going to mainstream education**

2.4 MOST FREQUENT ICD-10 CODES

2.4.1 ICD-10 Index, co-morbid and associated disorders

2.4.1.1 In general

In Appendix 4 to Chapter 2, an overview of the ICD-10 index, co-morbid and associated disorders in the sample is provided. Table 17 resumes the most prevalent and well-known disorders.

Most frequent index disorders are 'F81-Specific developmental disorders of scholastic skills' (17.81%), 'F70-Mild mental retardation' (17.70%), 'F80-Specific developmental disorders of speech and language' (13.47%), 'F84-Pervasive developmental disorders' (11.92%), 'F90-Hyperkinetic disorders' (11.09%) and 'H90-Conductive and sensorineural hearing loss' (5.71%).

Most frequent co-morbid disorders are nearly the same as the index disorders but in another sequence, except 'F82-Specific developmental disorder of motor function' (18.06%) and 'F98-Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence' (5.58%).

Most frequent associated disorders are 'R41-Other symptoms and signs involving cognitive functions and awareness, for example amnesia or disorientation' (16.69%), 'Z62-Other problems related to upbringing, for example inadequate parental supervision, neglect or overprotection' (9.13%), 'Z63-Other problems related to primary support group, including family circumstances, for example divorce, death or inadequate family support' (8.42%).

For practical reasons, only the most frequent disorders were analysed.

Table 17: ICD-10 Index, co-morbid and associated disorders (All participating centres)

ICD-10 code	Name	Index disorder		Co-morbid disorder		Associated disorder	
		N	%	N	%	N	%
F32	Depressive episode	20	0.41	42	0.86		
F41	Other anxiety disorders	29	0.59	86	1.75		
F43	Reaction to severe stress, and adjustment disorders	10	0.20	24	0.49		
F70	Mild mental retardation	870	17.70	225	4.59		
F71	Moderate mental retardation	181	3.69	57	1.16		
F72	Severe mental retardation	34	0.69	23	0.47		
F73	Profound mental retardation	28	0.57	31	0.63		
F80	Specific developmental disorders of speech and language	661	13.47	1216	24.78	2	0.04
F81	Specific developmental disorders of scholastic skills	874	17.81	746	15.20	1	0.02
F82	Specific developmental disorder of motor function	176	3.59	886	18.06	2	0.04
F83	Mixed specific developmental disorders	85	1.73	118	2.40		
F84	Pervasive developmental disorders	585	11.92	271	5.52		
F90	Hyperkinetic disorders	544	11.09	552	11.25	2	0.04
F91	Conduct disorders	61	1.24	171	3.48	2	0.04
F93	Emotional disorders with onset specific to childhood	46	0.94	225	4.59	2	0.04
F94	Disorders of social functioning with onset specific to childhood and adolescence	66	1.34	131	2.67	1	0.02
F95	Tic disorders	1	0.02	29	0.59		
F98	Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence	72	1.47	274	5.58	1	0.02
G40	Epilepsy					88	1.79
G80	Cerebral palsy	69	1.41	20	0.41	2	0.04
H90	Conductive and sensorineural hearing loss	280	5.71	34	0.69	1	0.02
P07	Disorders related to short gestation and low birth weight, not elsewhere classified					59	1.20
Q90	Down's syndrome					52	1.06
Q99	Other chromosome abnormalities, not elsewhere classified					59	1.20
R41	Other symptoms and signs involving cognitive functions and awareness					819	16.69
Z60	Problems related to social environment					149	3.04
Z61	Problems related to negative life events in childhood					200	4.08
Z62	Other problems related to upbringing					448	9.13
Z63	Other problems related to primary support group, including family circumstances					413	8.42

2.4.1.2 *Clustering: mental retardation, developmental disorders and behavioural disorders*

Combination of all subcategories within the ICD-10 clusters "mental retardation", "developmental disorders" and "behavioural disorders" resulted in the following numbers of patients per cluster (see Table 17 and Appendix 4 to chapter 2):

- 1122 patients (22,9%) with the index disorder 'mental retardation' (F70 to F79)
- 2394 patients (48,8%) with the index disorder 'developmental disorder' (F80 to F89)
- 822 patients (16,8%) with the index disorder 'behavioural disorder' (F90 to F98).

The conclusion can be drawn that 4338 of the 4907 patients (88.4%) in the sample are explained by the three clusters 'mental retardation', 'developmental disorders' and 'behavioural disorder'.

2.4.1.3 *Main ICD-10 index, co-morbid and associated disorders: in detail*

More details on codifications within each main index, co-morbid or associated disorder can be found in Appendix 5 to chapter 2.

Examples of detail codifications within main index and co-morbid disorders:

- In the main index disorder 'Specific developmental disorders of scholastic skills': 'Mixed disorder of scholastic skills' (64.1%) - 'Specific reading disorder' (19.82%) - 'Specific disorder of arithmetical skills' (10.87%).
- In the main index disorder 'Specific developmental disorders of speech and language': 'Expressive language disorder' (33.6%) - 'Receptive language disorder' (25.26%).
- In the main index disorder 'Pervasive developmental disorders': 'Childhood autism' (52.8%) - 'Atypical autism' (34.53%).
- In the main index disorder 'Conductive and sensorineural hearing loss': 'Sensorineural hearing loss, bilateral' (81.4%) - 'Sensorineural hearing loss, unspecified' (11.43%).

The more detailed analyses within main co-morbid disorders showed a high similarity with detailed analyses for the main index disorders.

Examples of detail codifications within associated disorders:

- In the main associated disorder 'Other problems related to upbringing': 'Inadequate parental supervision and control' (31.5%).
- In the main associated disorder 'Other problems related to primary support group, including family circumstances': 'Disruption of family by separation and divorce' (34.1%).

The main associated disorder 'R41.8-Other and unspecified symptoms and signs involving cognitive functions and awareness' has been used in the Dutch speaking rehabilitation centres as an artificial term for the registration of 'borderline intellectual functioning' (see 2.1.2 for the registration procedure and 2.8 for further analysis of this subcategory). The registration of R41.8 in the French speaking rehabilitation centres was not specifically mentioned and is therefore covered by other registrations (for example F83). This means that the 16.69% of the R41-codes were all registered in the Dutch speaking centres. The actual frequency of the R41.8 code is 22.38%.

2.4.1.4 *Main ICD-10 disorders: in detail*

The distinction of index disorder/co-morbid disorder may be dependent of the point of the view of the team members when they have to decide which disorder has most impact on the daily live of the patient. Therefore, analyses of the prevalence of the main disorders were made, independently of that distinction (see Table 18).

In comparison with the abovementioned analyses (Table 17), an almost similar ordering and prevalence can be seen. The detailed analysis can be found in Appendix 5 to Chapter 2.

Table 18: Main ICD-10 disorders (index or co-morbid disorder)

Disorder	N	% within the total sample
F80 'Specific developmental disorders of speech and language'	1879	38.2
F81 'Specific developmental disorders of scholastic skills'	1621	33
F90 'Hyperkinetic disorders'	1098	22.4
F70 'Mild mental retardation'	1095	22.2
F84 'Pervasive developmental disorders'	856	17.3
F98 'Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence'	347	7.1
H90 'Conductive and sensorineural hearing loss'	315	6.5

2.4.1.5 *By province*

The most common index disorders, categorized by the province of the rehabilitation centre (according to participating patients in these centres) are illustrated in Table 19. As abovementioned, 'Brabant' contains all rehabilitation centres situated in Flemish Brabant, Walloon Brabant and Brussels. Due to the anonymous processing of the data no information was obtained concerning the maximum capacity of the participating centres. Therefore, the analyses were done by using the total number of patients cooperating in this study.

Table 19: Six most common ICD-10 index disorders and their % within each province

	Antwerp		Brabant		West-Flanders		East-Flanders		Hainaut		Liège		Limburg		Namur	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
F81 'Specific developmental disorders of scholastic skills'	11	11.8	47	13.2	202	19.8	455	20.2	10	5.7	52	6.7	97	54.2	0	0
F70 'Mild mental retardation'	25	26.9	26	7.3	170	16.7	438	19.5	24	13.7	178	23	9	5	0	0
F80 'Specific developmental disorders of speech and language'	8	8.6	51	14.4	181	17.7	291	12.9	29	16.6	67	8.7	34	19	0	0
F84 'Pervasive developmental disorders'	10	9.3	44	12.4	99	9.7	308	13.7	9	5.1	108	14	7	3.9	0	0
F90 'Hyperkinetic disorders'	6	6.5	9	2.5	144	14.1	323	14.5	9	5.1	49	6.3	4	2.2	0	0
H90 'Conductive and sensorineural hearing loss'	27	29.0	124	34.9	45	4.4	84	3.7	0	0	0	0	0	0	0	0
Total*	93	92.1	355	84.7	1020	82.4	2249	84.5	175	46.2	774	58.7	179	84.3	0	0

*Total number of participating patients per province (see Table 12)

Table 20 provides an overview when analyses were performed without taking the number of participating patients in each province in account.

Table 20: Six most common ICD-10 index disorders within each province and their % per province within each index disorder

	Antwerp		Brabant		West-Flanders		East-Flanders		Hainaut		Liège		Limburg		Namur	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%
F81 'Specific developmental disorders of scholastic skills'	11	1.3	47	5.4	202	23.1	455	52.1	10	1.1	52	5.9	97	11.1	0	0
F70 'Mild mental retardation'	25	2.9	26	3.0	170	19.5	438	50.3	24	2.8	178	20.5	9	1.0	0	0
F80 'Specific developmental disorders of speech and language'	8	1.2	51	7.7	181	27.4	291	44.0	29	4.4	67	10.1	34	5.1	0	0
F84 'Pervasive developmental disorders'	10	1.7	44	7.5	99	16.9	308	52.6	9	1.5	108	18.5	7	1.2	0	0
F90 'Hyperkinetic disorders'	6	1.1	9	1.7	144	26.5	323	59.4	9	1.7	49	9.0	4	0.7	0	0
H90 'Conductive and sensorineural hearing loss'	27	9.6	124	44.3	45	16.1	84	30.0	0	0	0	0	0	0	0	0
Total**	87	2.3	301	7.9	841	22.1	1899	49.8	81	2.1	454	11.9	151	4.0	0	0

**Total number of the 6 main index disorders per province (see Table 12)

The main index disorders are mostly (from 44% to 59%) represented in rehabilitation centres in East-Flanders. This is within expectations because most of the rehabilitation centres are located in this province. An exception is found for 'Conductive and sensorineural hearing loss'. This disorder is mainly (44.3%) represented in rehabilitation centres in Brabant, followed by East-Flanders. It should be noted that in the sample, no patients with hearing loss as an index disorder are represented in the sample from the rehabilitation centres in Hainaut, Liège, Limburg or Namur (or Luxembourg), so maybe the Brabant centre is recruiting many patients from these (French speaking) provinces. Another explanation can be that no 'Conductive and sensorineural hearing loss' are registered due to the fact that other, not participating rehabilitation centres in these provinces treat these patients.

In addition to this, the main index disorders in the sample are not represented in the rehabilitation centre in Namur. Analysis of the rehabilitation centre in Namur, showed a specialisation in 'Cerebral palsy' (G80) and 'Profound mental retardation' (F73), namely 38 patients (61%) have 'Cerebral palsy' and 14 patients (23%) have 'Profound mental retardation' as an index disorder. These disorders are not included in the main index disorders.

- **The six most prevalent ICD-10 index disorders are:**
- **- F81 'Specific developmental disorders of scholastic skills'**
- **- F70' Mild mental retardation'**
- **- F80 'Specific developmental disorders of speech and language'**
- **- F84 'Pervasive developmental disorders'**
- **- F90 'Hyperkinetic disorders'**
- **- H90 'Conductive and sensorineural hearing loss'**
- **Of all the patients in the sample 88.4% is explained by the three clusters 'mental retardation', 'developmental disorders' and 'behavioural disorders'**
- **There is a high similarity between the most frequent ICD-10 index disorders and the most frequent ICD-10 co-morbid disorders : 4 of the 6 categories for co-morbid disorders are also used as disorders in the index category (F80, F81, F84 and F90), which indicates the great exchangeability in labelling an disorder as index or co-morbid**
- **The three most prevalent ICD-10 co-morbid disorders are: "Specific developmental disorders of speech and language", "Specific developmental disorder of motor function" and "Specific developmental disorders of scholastic skills".**

2.4.1.6 ICD-10 Index, co-morbid and associated disorders: by official language of the rehabilitation centre

Table 21 outlines the six most important index disorders, categorized by the official language of the rehabilitation centre. The column '% within ICD-10 code' outlines the prevalence of the ICD-10 code, separately for the Dutch and French speaking centres. This percentage depends on the number of participants in the centres (there are more patients in the Dutch speaking rehabilitation centres than in the French speaking rehabilitation centres). Therefore, the percentage was also calculated based on this difference, so the column '% within Dutch/French centres' provides us with an overview of the prevalence of the ICD-10 code in the Dutch and the French speaking rehabilitation centres. An extra remark should be made concerning the difference in the number of participating patients between the Dutch speaking centres and the French speaking centres. This makes comparison difficult and conclusions should be drawn with care. In this study, a "difference" between Dutch and French centres was defined as a difference of minimal 5%.

Table 21: Six most frequent ICD-10 index disorders within the language of the rehabilitation centre

Index disorders	Dutch			French		
	N	% within ICD-10 code	% within Dutch centres	N	% within ICD-10 code	% within French centres
F81 'Specific developmental disorders of scholastic skills'	798	91.3	21.8	76	8.7	6.1
F70 'Mild mental retardation'	655	75.3	17.9	215	24.7	17.2
F80 'Specific developmental disorders of speech and language'	528	79.9	14.4	133	20.1	10.6
F84 'Pervasive developmental disorders'	445	76.1	12.2	140	23.9	11.2
F90 'Hyperkinetic disorders'	486	89.3	13.3	58	10.7	4.6
H90 'Conductive and sensorineural hearing loss'	156	55.7	4.3	124	44.3	9.9
Total	3068		83.9	746		59.7

Compared to French patients, a higher proportion of Dutch patients had the index disorder 'Specific developmental disorders of scholastic skills' and 'hyperkinetic disorders'. French speaking centres report more often than the Dutch speaking centres 'conductive and sensorineural hearing loss', but it should be kept in mind that the French NOK centres are probably not fully representative.

Together, the 6 most frequent index disorders in the Dutch speaking centres account for 83.9%, whereas they only account for 59.7% in the French speaking centres. Further analysis of the missing 40.3% in the French centres can be found in Appendix 5 to chapter 2. The next four most prevalent index disorders in the French centres are 'Moderate mental retardation' (7.2%), 'Mixed specific developmental disorders' (4.6%), 'Disorders of social functioning with onset specific to childhood and adolescence' (4.1%), followed by "Cerebral palsy" (3.4%)

More details on the 6 most important co-morbid disorders, categorized by the language of the rehabilitation centre, can be found Appendix 5 to chapter 2. No differences were found between the 6 most important co-morbid disorders in Dutch and in French centres. Among the remaining co-morbid disorders, "disorders of behaviour, emotional and social functioning" or "conduct problems" were somewhat more frequent in French than in Dutch centres.

The most frequent associated disorders (apart from 'Other symptoms and signs involving cognitive functions and awareness', only registered in Dutch centres), as mentioned in Table 21, are more common in the French speaking centres than in the Dutch speaking centres. It are the Z-codes 'Other problems related to upbringing' and 'Other problems related to primary support group, including family circumstances'.

Key points

- **In the Dutch speaking centres, the six most prevalent index disorders account for 84% of the index disorders and in the French speaking participating centres for 60% of the index disorders. The next four most prevalent index disorders in the French centres are 'Moderate mental retardation' (7.2%),'Mixed specific developmental disorders' (4.6%), 'Disorders of social functioning with onset specific to childhood and adolescence' (4.1%), followed by "Cerebral palsy" (3.4%)**
- **The six most frequent co-morbid disorders are the same in Dutch and French centres.**
- **Specific for the Dutch centres is the associated disorder 'Other symptoms and signs involving cognitive functions and awareness (due to registration procedures, see methodology)**
- **The two most frequent associated disorders (Z-codes related to upbringing and family circumstances) are the same in Dutch and French centres. However, they are more frequently registered in French speaking centres.**

2.4.1.7 ICD-10 Index, comorbid and associated disorders: NOK or PSY

Table Table 22 outlines an overview of the main index disorders, categorized by NOK and PSY rehabilitation centres.

Table 22: Six most frequent ICD-10 index disorders within NOK/PSY

Index disorders	NOK			PSY		
	N	% within ICD-10 code	% within NOK	N	% within ICD-10 code	% within PSY
F81 'Specific developmental disorders of scholastic skills'	603	69	23.9	271	31	11.4
F70 'Mild mental retardation'	343	39.4	13.6	527	60.6	22.1
F80 'Specific developmental disorders of speech and language'	406	61.4	16.1	255	38.6	10.7
F84 'Pervasive developmental disorders'	223	38.1	8.8	362	61.9	15.2
F90 'Hyperkinetic disorders'	299	55	11.9	245	45	10.3
H90 'Conductive and sensorineural hearing loss'	280	100	11.1	0	0	0
Total	2154		85.4	1660		69.6

The 5 most prevalent index disorders (not including "Conductive and sensorineural hearing loss" which only belongs to NOK centres) account for 74.3% in NOK centres and 69.6% in PSY centres. This highlights the large similarity between NOK and PSY centres.

Nevertheless, some differences exist. In NOK rehabilitation centres, the most prevalent index disorder is 'Specific developmental disorders of scholastic skills' (23.9% versus 11.4% in PSY rehabilitation centres). In PSY rehabilitation centres, the most prevalent index disorder is 'Mild mental retardation' (22.1% versus 13.6% in NOK rehabilitation centres). The second most prevalent index disorder in NOK centres is 'Specific developmental disorders of speech and language' (16.1% versus 10.7% in PSY centres). In PSY centres the second most prevalent index disorder is 'pervasive developmental disorders' (15.2% versus 8.8% in NOK centres).

For the most common ICD-10 co-morbid and associated disorders, categorized by NOK and PSY rehabilitation centre, more details can be found in the Appendix 5 to chapter 2.

Briefly, the 6 most prevalent co-morbid disorders are the same in NOK and PSY rehabilitation centres, although their prevalence is different: e.g. 'Specific developmental disorders of speech and language' (25.6% in NOK; 16.8% in PSY), 'Specific developmental disorder of motor function' (26.3% in NOK; 9.4% in PSY centres), 'Specific developmental disorders of scholastic skills' (17.4% in NOK; 12.5% in PSY). For the associated disorders, "Z-codes" e.g. 'Other problems related to upbringing', are slightly more often registered in PSY centres, as expected.

In conclusion, although some differences exist, overall no large difference is perceived between NOK and PSY.

2.4.1.8 By official language of the centres and by NOK or PSY

When comparing main ICD-10 index disorders for Dutch and French speaking NOK respectively PSY centres, the number of participants in one diagnostic category (especially in the French speaking centres) became too small to judge on differences (see Table 13). The representativeness of the French NOK centres was already questioned earlier (see Table 21) In Appendix 5 to Chapter 2 detailed information concerning these analyses can be consulted.

Key points

- **Although some differences exist, overall no large differences are perceived between NOK and PSY.**
- **'Specific developmental disorders of scholastic skills' is the most prevalent ICD-10 index disorder in participating NOK centres whereas the most prevalent in PSY centres is 'Mild mental retardation'.**
- **The six most prevalent ICD-10 co-morbid disorders are the same in NOK and PSY rehabilitation centres, but their prevalence is different.**

2.4.2 ICD-10 Co-morbid and associated disorders within the main index disorders

2.4.2.1 Number of co-morbid and associated disorders within the main ICD-10 index disorders

Table 23 shows the total number of co-morbid disorders within the main index disorders in the sample.

In general, 23% does not have any co-morbid disorder and more than 70% have at least one co-morbid disorder. Only for 'Conductive and sensorineural hearing loss' the percentage of no co-morbid disorders is higher, namely 45.4%.

Table 23: Total number of co-morbid disorders within the main ICD-10 index disorders

	Number of co-morbidities							
	0		1		2		3	
Index disorders	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
F81 'Specific developmental disorders of scholastic skills'	268	30.7	399	45.7	167	19.1	40	4.6
F70 'Mild mental retardation'	267	30.7	322	37.0	184	21.1	97	11.1
F80 'Specific developmental disorders of speech and language'	165	25.0	267	40.4	169	25.6	60	9.1
F84 'Pervasive developmental disorders'	184	31.5	212	36.2	138	23.6	51	8.7
F90 'Hyperkinetic disorders'	123	22.6	206	37.9	158	29.0	57	10.5
H90 'Conductive and sensorineural hearing loss'	127	45.4	55	19.6	63	22.5	35	12.5
Total	1134	23.1	1461	29.8	879	17.9	340	6.9

In Appendix 6 to chapter 2, an overview of the total number of associated disorders for the main index disorders in the sample is provided; 51% of the patients within the main index disorders has no associated disorder. Further analyses, also shown in Appendix 6 to chapter 2, were made of the patients with a main index disorder and no co-morbid disorders. It is shown that about 50% of these patients have no associated disorder, about 30% has 1 associated disorder and about 10% has 2 or 3 associated disorders.

It can be concluded that about 10% of the patients with a main index disorder has no co-morbid and no associated disorder.

Key points

- **Of the main ICD-10 index disorders 23.1% respectively 29.8%, 19.9% and 6.9% have no, 1, 2 and 3 co-morbidities**
- **Of the main ICD-10 index disorders 51% has no associated disorders.**
- **About 50% of the ICD-10 index disorders without co-morbid disorders has no associated disorders, +-30% has 1 associated disorder and +-10% has 2 or 3 associated disorders**
- **This means that about 10% of the main ICD-10 index disorders has no co-morbid disorder nor an associated disorder.**

2.4.2.2 Specificity of co-morbid and associated disorders within the main ICD-10 index disorders

In Table 17 and in Appendix 6 to Chapter 2 an overview of the main co-morbid and associated disorders within the main ICD-10 index disorders is presented.

"Mild mental retardation" nor "Conductive and sensorineural hearing loss" are among the 6 most frequent co-morbidities; whereas "Specific developmental disorder of motor function" and, to a lesser degree, "Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence" are frequent.

Although in the ICD-10, 'Mental retardation (F70-79)' is an exclusion criterion for the diagnosis of 'Specific developmental disorders of speech and language', the sample comprised this index disorder together with 'Specific developmental disorders of speech and language' in 255 patients (29.3%). A person with mild mental retardation can be retarded in different areas, and emotional, cognitive, behavioural as well as social functions can all be part of the retardation. Usually these persons have a certain harmonic profile in all these domains. When negative fluctuations occur, it is possible to diagnose a secondary disorder next to the mental retardation, although it is an exclusion criterion in the ICD-10. For example, language disorders can be registered together with 'Mild mental retardation' when the language disorders are more prominent than would be expected from the "mild mental retardation". Probably this is the case in this research, although it is also possible that in practice the teams neglect the exclusion criteria of the ICD-10.

As to the specificity of the associated disorders within the main index disorders, R41.8 or Z-codes related to upbringing or family circumstances are most prevalent and no large differences are perceived between the main index disorders. An exception is 'Conductive and sensorineural hearing loss", for which associated disorders are mainly related to hearing problems (see later).

2.4.3 Disciplines within the main ICD-10 index disorders, co-morbidities and associated disorders

As disciplines were not registered in the French speaking rehabilitation centres, the following analyses concern only the data from Dutch speaking centres.

2.4.3.1 *In general*

For the Dutch data, the type of discipline for each patient was registered (see Appendix 2 to Chapter 2 which outlines the registered variables in the Dutch and French speaking rehabilitation centres). Most common therapies that the patients receive (see Appendix 9 to chapter 2) are speech therapy (89.6%), occupational therapy (75.9%), physiotherapy (67.9%), psychotherapy (32.0%) and psychological assistance (11.7%). Face-to-face care of other therapists like audiologists (9.3%), social assistants (4.4%), physicians (2.2%) or tutors (1.1%) are uncommon. Most of the patients were treated by 3 disciplines (57.4%), 4 disciplines (19.8%) or 2 disciplines (18.1%). It is rare to receive face-to-face care of only 1 discipline (0.9%) or 5 or more disciplines (3.8%). Physiotherapy and psychomotor therapy are brought together in one category named 'physiotherapy' because of the high overlap between these disciplines. In the sample, 361 patients (10.3%) received both therapies.

In both the PSY and NOK conventions, the obligated provision of at least three different disciplines, provided by three different therapists per month and per patient, is described (see Chapter 1). In this sample, the rehabilitation centres registered next to a total of 81% of 3 or more disciplines, also 19% of less than 3 disciplines.

A first explanation is that physiotherapy and psychomotor therapy were brought together in one category (physiotherapy) in the data analysis because the distinction is not always very clear (10.3% of the patients received both therapies). Another explanation is the fact that these centres registered the most common disciplines during one rehabilitation week, so the exceptional therapy provided once a month (for example the physician) was not registered. The frequency of registering 5 or more disciplines is low and probably contains the disciplines that are sporadically provided (physician, social worker…). Some patients (N=40) even receive 7 disciplines. Further analyses of this group did not discover possible explanations for this finding.

2.4.3.2 *Disciplines in NOK and PSY*

An overview of the number of disciplines organized in Dutch NOK and PSY rehabilitation centres is provided in Table 24 Mainly 3 disciplines are involved in rehabilitation.

Table 24: Number of disciplines in participating Dutch NOK/PSY

Number of disciplines	NOK		PSY		Total	
	N	%	N	%	N	%
1	27	1.3	4	0.3	31	0.9
2	511	25.1	119	8.3	630	18.1
3	1110	54.6	884	61.5	1994	57.4
4	312	15.3	374	26.0	686	19.8
5	38	1.9	41	2.9	79	2.3
6	12	0.6	0	0	12	0.3
7	24	1.2	16	1.1	40	1.2
Total	2034	100	1438	100	3472	
Missing	186					

Further analyses of the 186 missing cases revealed that two rehabilitation centres (1 in East-Flanders and 1 in West-Flanders) did not register the intervening disciplines and therefore counted together for 163 missing cases of the 186. The other missing cases are divided over all the Dutch speaking rehabilitation centres and are probably due to errors during the registration process.

2.4.3.3 *Number of disciplines*

Table 25 illustrates the total number of disciplines within the main index disorders in the Dutch speaking rehabilitation centres. There are no main index disorders with an extraordinary total number of disciplines. A total number of 3 disciplines is most common.

Table 25: Total number of disciplines within the main index disorders (Dutch centres)

	Total number of disciplines													
	1		2		3		4		5		6		7	
Index disorders	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
F81	4	0.5	196	26.7	411	56.0	110	15.0	4	0.5	0	0	9	1.2
F70	1	0.2	68	11.2	375	62.0	138	22.8	11	1.8	2	0.3	10	1.7
F80	3	0.6	90	18.1	290	58.5	87	17.5	16	3.2	4	0.8	6	1.2
F84	5	1.2	64	14.8	216	49.9	124	28.6	17	3.9	1	0.2	6	1.4
F90	4	0.8	98	20.5	268	56.2	91	19.1	11	2.3	0	0	5	1.0
H90	5	3.3	33	22.0	79	52.7	28	18.7	4	2.7	0	0	1	0.7

In theory less than 3 disciplines is not possible due to restrictions from the RIZIV/INAMI conventions. Explanations for this finding can be found earlier in this chapter.

2.4.3.4 *Kind of disciplines*

In Appendix 9 to Chapter 2, the registered disciplines within the different main index disorders are presented.

Speech and occupation therapy are in 60 to 80% of the cases involved in the treatment for children within all the main index disorders (except 'conductive and sensorineural hearing loss'), except for occupational therapy for children with 'Pervasive developmental disorders' (where it is only involved in 50 to 60%). Another exception are children with 'conductive and sensorineural hearing loss" for whom speech therapy is provided in 50% of the cases and occupational therapy in 20-30% of the cases.

Physiotherapy is in 50 to 60% of the cases involved in the treatment for children within all of the main index disorders (except 'conductive and sensorineural hearing loss' where it is 20%).

Psychotherapy is in 30 to 40 % of the cases involved in the treatment for children with 'Pervasive developmental disorders' and 'Hyperkinetic disorders' and for these children the care of psychological assistant is involved in 10 to 20% of the cases. For the other main index disorders, psychotherapy is only involved in 10 to 30% of the cases and the psychological assistant in less than 10%.

For children with 'conductive and sensorineural hearing loss' audiotherapy is also frequently provided (40%).

It is worthwhile to compare these findings with the 1999 data in the RIZIV/INAMI study (Leefbaarheidsstudie RIZIV, 2003). In this study, implying Dutch as well as French NOK/PSY centres, the % (of the total number of therapy hours per week available per patient) of the different disciplines available per patient in NOK-centres was: speech therapy (50%), physiotherapy and psychomotor therapy (15%), psychotherapy (11%), occupational therapy (9%). For PSY centres, this was: speech therapy (34%), physiotherapy and psychomotor therapy (19%), occupational therapy (19%), psychotherapy (13%).

Although 'psychotherapy' is common for all main index disorders, the provision is much higher for children with 'Pervasive developmental disorder' and 'Hyperkinetic disorder'. No literature is available on the percentages of children in these diagnostic groups that need psychological support and also little evidence exist on the outcome of psychotherapy.

Maybe the extended knowledge of psychotherapists concerning these latter disorders makes them more favourable for providing the interventions themselves, whereas for other disorders, speech therapy and occupational therapy cover already most problem areas. Another explanation could be that there is an insufficient number of psychotherapeutic personnel that makes it necessary to set priorities.

2.4.3.5 Number of disciplines linked to the number of co-morbid disorders

In Table 26, an overview is provided of the number of disciplines linked to the number of co-morbid disorders. It is not common to provide more disciplines when a patient has more co-morbiditities.

Table 26: Number of disciplines linked to the number of co-morbid disorders (Dutch centres)

	Number of co-morbid disorders							
	0		1		2		3	
Number of disciplines	N	%	N	%	N	%	N	%
1	12	1.0	11	0.8	6	0.8	2	0.8
2	182	15.9	253	18.9	153	21.0	42	16.2
3	686	60.0	768	57.3	392	53.8	148	56.9
4	212	18.5	261	19.5	147	20.2	66	25.4
5	31	2.7	29	2.2	18	2.5	1	0.4
6	5	0.4	5	0.4	2	0.3	0	0
7	16	1.4	13	1.0	10	1.4	1	0.4

A possible explanation for the finding that the number of disciplines is not linked to the number of co-morbid disorders is that the complexity of the child's problems depends also on the main problem. The main problem can be complex as such, causing many problems in overall daily life, e.g. mental handicap or autism. It should also be noted that 3 disciplines are required within the Belgian NOK/PSY rehabilitation centres (see conventions in Appendix to Chapter 1) so the variability in number of disciplines as such is low. Registration of these disciplines could also have been based on a weekly basis, this can also explain why sometimes 2 disciplines are registered.

2.4.3.6 Number of disciplines linked to the number of associated disorders

It is not common to provide more disciplines when a patient has more associated disorders (see Appendix 9 to Chapter 2).

Key points

- **For all the main ICD-10 index disorders speech therapy, occupational therapy, physiotherapy and psychotherapy are the most frequent involved disciplines; for 'Conductive and sensorineural hearing loss' audiotherapy is also frequent.**
- **It is not common to provide more disciplines when a patient has more co-morbid or associated disorders**

2.5 DISORDERS IN RIZIV/INAMI CONVENTIONS[p]

2.5.1 Disorders in RIZIV/INAMI Conventions: NOK and PSY centres

When discussing disorders in RIZIV/INAMI conventions, it should be kept in mind that the disorders reimbursed in NOK respectively PSY centres are not completely the same (see Chapter "Characteristics of RIZIV/INAMI conventions"). This makes it necessary to discuss NOK and PSY centres separately.

Table 27 shows that in NOK rehabilitation centres most frequent 'disorders in RIZIV/INAMI conventions' are 'Mental retardation' (21.3%), 'Learning disorders' (20.3%) and 'Borderline intellectual functioning' (23.55% of which 16% is registered as 'Borderline intellectual functioning with harmonic profile'). Table 28 illustrates that in PSY rehabilitation centres most frequent 'disorders in RIZIV/INAMI conventions' are 'Mental retardation' (41.4%), 'Borderline intellectual functioning' (25.14% of which 16.9% is registered as 'Borderline intellectual functioning with harmonic profile'), and 'Learning disorders' (8.5%). These are also the most prevalent categories in the study from the RIZIV (Leefbaarheidsstudie RIZIV, 2003); successively 34.4%, 32.8.1% and 6.1%).

Remarkable is the great overlap in target groups: all target groups in NOK rehabilitation centres are also registered in PSY rehabilitation centres, except 'Hearing disorders', 'Laryngectomy' and 'Stuttering' which are not allowed in PSY centres. These NOK-specific target groups represent a minority within the NOK population (15.65%).

On the other side, all target groups in PSY rehabilitation centres, except 'Cerebral palsy', 'Severe conduct disorders', 'Mood disorders' and 'Schizophrenia' are also registered in NOK rehabilitation centres. These PSY-specific target groups represent a minority within the PSY rehabilitation centres (6.9%). This confirms previous findings (Leefbaarheidsstudie, RIZIV 2003: 89.08% of the population is represented in the target groups that are shared in the NOK and PSY conventions).

Table 27: Disorders in RIZIV/INAMI conventions in NOK

Disorders in RIZIV/INAMI conventions	N	%
'Mental retardation'	525	21.32
'Learning disorders'	500	20.30
'Borderline intellectual functioning with harmonic profile'	393	15.96
'Hearing disorders <6years'	228	9.26
'Hyperkinetic disorders'	209	8.49
'Borderline intellectual functioning with disharmonic profile'	187	7.59
'Language developmental disorders'	138	5.60
'Hearing disorders cochlear implant'	64	2.60
'Stuttering'	28	1.14
'Brain damage'	26	1.06
'Pervasive developmental disorders'	129	5.24
'Laryngectomy, glossectomy'	16	0.65
'Hearing disorders >70dBA and >6 years'	14	0.57
'Borderline intellectual functioning'	6	0.24
Total	2463	100

All subcategories within hearing disorders contain 306 patients (12.42%).

p See RIZIV/INAMI conventions in Appendix to Chapter 3

Table 28: Disorders in RIZIV/INAMI conventions in PSY

Disorders in RIZIV/INAMI conventions	N	%
'Mental retardation'	984	41.36
'Borderline intellectual functioning with harmonic profile'	401	16.86
'Learning disorders'	201	8.45
'Borderline intellectual functioning with disharmonic profile'	197	8.28
'Hyperkinetic disorders'	158	6.64
'Cerebral palsy'	111	4.67
'Pervasive developmental disorders'	135	5.67
'Language developmental disorders'	52	2.19
'Severe conduct disorders'	25	1.05
'Mood disorders'	24	1.01
'Brain damage'	5	0.21
'Schizophrenia'	4	0.17
'Borderline intellectual functioning'	2	0.08
Total	2379	100

2.5.2 By language of the rehabilitation centres

In Table 29, a summarizing overview with a clustering of the most common disorders in RIZIV/INAMI conventions in the Dutch and French speaking NOK and PSY centres is presented. More detailed tables can be found in the Appendix 11 to chapter 2.

Table 29: Overview of the most common disorders in RIZIV/INAMI conventions in Dutch and French NOK and PSY speaking rehabilitation centres

	NOK			PSY		
Disorders in RIZIV/INAMI conventions	% Dutch	% French[q]	%Total	% Dutch	% French	%Total
'Mental retardation'	20.2	27.6	21	34.0	54.1	41
'Borderline intellectual functioning'	25.0	17.5	24	26.7	22.5	25
'Learning disorders'	23.1	5.0	20	13.0	0.6	8
'Hyperkinetic disorders	9.7	1.6	8	9.7	1.4	7
'Pervasive developmental disorders'	5.9	1.3	5	9.9	7.6	6
'Language developmental disorders'	5.2	8.0	6	3.3	0.2	2
'Hearing disorders[r]	8.4	34.5	12	-	-	-
'Brain damage' and 'cerebral palsy'	1.2	0.5	1	2.8	8.5	5
Total	97.5	95.5	97	96.6	86.4	94

q Probably not fully representative, see chapter 2.2

r hearing disorders<6years', 'hearing disorders>70dBA and <6years' and 'hearing disorders cochlear implant' together account for 8.4% in the Dutch NOK centres and for38.5% in the French NOK centres

A difference between French and Dutch speaking centres is registered when that difference is minimum 5%.

For the NOK rehabilitation centres 'Hearing disorders' and 'Mental retardation' were more present in the French speaking NOK rehabilitation centres, whereas 'Learning disorders', 'Hyperkinetic disorders' and 'Borderline intellectual functioning (with harmonic and disharmonic profile)' were more present in the Dutch speaking NOK rehabilitation centres. However, it should be kept in mind that the data for the French NOK centres might not be fully representative (see 2.2 of this chapter)

For the PSY rehabilitation centres 'Mental retardation' was more present in the French speaking PSY rehabilitation centres, whereas 'Learning disorders' and 'Hyperkinetic disorders' were more present in the Dutch speaking PSY rehabilitation centres.

Key points

- **Conclusions for the RIZIV/INAMI classification in NOK and PSY centres:**
- **The three largest RIZIV/INAMI groups are: 'Mental retardation', 'Borderline intellectual functioning' and 'Learning disorders'.**
- **There exists a large overlap between the population of NOK and PSY centres; and the NOK-specific respectively PSY-specific target groups represent only a minority of the patient population**
- **More registered disorders in PSY than in NOK: 'Mental retardation' (respectively 41% and 21%)**
- **More registered disorders in NOK than in PSY: 'Learning disorders' (respectively 20% and 8%).**
- **All other (overlapping) disorders in RIZIV/INAMI conventions are equally registered in NOK and PSY rehabilitation centres**
- **More registered disorder in French than in Dutch speaking PSY centres: 'Mental retardation' and 'Brain damage, Cerebral palsy'**
- **More registered disorders in Dutch than in French speaking PSY centres: 'Learning disorders' and 'Hyperkinetic disorders'.**

2.6 COMPLAINT BY REGISTRATION

Complaints by registration were only registered by the Dutch rehabilitation centres. All Tables and more specific information concerning analyses with 'complaints by registration' can be found in Appendix 10 and Appendix 12 to Chapter 2.

In general most frequent 'complaints by registration' were 'Developmental retardation' (26.3%), 'Learning problems' (21.4%) and 'Language/speech problems' (15.1%). Further, only for 'Developmental disorders of scholastic skills' and 'Conductive and sensorineural hearing loss' the main 'complaint by registration' matches the exact diagnoses in more than 50% of the cases.

Key points

- **Only for 'Developmental disorders of scholastic skills' and 'Conductive and sensorineural hearing loss' the main 'complaint by registration' matches the exact diagnoses in more than 50% of the cases. Hence the diagnostic phase in the rehabilitation centres is important.**

2.7 COMPARISON OF THE 2 CLASSIFICATIONS: RIZIV/INAMI AND ICD-10

In Table 30-B, the five most frequent index ICD-10 categories are combined with the five most frequent RIZIV/INAMI convention disorders. In row A, the number is shown of the participants in the data sample (in NOK centres, in PSY centres, in NOK and PSY centres together) belonging to a specific ICD-10 category and at the same time to a specific RIZIV/INAMI convention disorder. In row B, these numbers are presented as a percentage of the total ICD-10 category (in NOK centres, in PSY centres, in NOK and PSY centres together). Some results are highlighted in paragraph 2.7.1 "RIZIV/INAMI conventions within the ICD-10 main index disorders". In row C, the same numbers are presented as a percentage of the total RIZIV/INAMI convention disorder (in NOK centres, in PSY centres, in NOK and PSY centres together). Some results are highlighted in paragraph 2.7.2 "ICD-10 main index disorders within RIZIV/INAMI conventions".

More detailed tables can also be found in the Appendix 13 to chapter 2.

2.7.1 RIZIV/INAMI conventions within the ICD-10 main index disorders

The aim of this paragraph is to describe where patients with a specific ICD-10 code are classified in the RIZIV/INAMI conventions. First, for the six most frequent ICD-10 codes the corresponding RIZIV/INAMI convention codifications in NOK centres respectively PSY centres are described. Next, the same exercise is made taking also into account the languages, for those subgroups with enough patients to make this exercise meaningful.

2.7.1.1 Which RIZIV/INAMI conventions within the ICD-10 main index disorders?

ICD-10 Specific developmental disorders of scholastic skills

Within the ICD-10 index disorder 'Specific developmental disorders of scholastic skills', the most common RIZIV/INAMI codification is 'Learning disorders', accounting for 65% (NOK) and 54% (PSY) of this ICD-10 group. The next most common RIZIV/INAMI codification within this ICD-10 group is "Borderline Intellectual Functioning": 25% (NOK) and 34% (PSY).

ICD-10 Mild mental retardation

Within the ICD-10 index disorder "Mild mental retardation", the most common RIZIV/INAMI codification is 'Mental retardation', accounting for 91% (NOK) and 92% (PSY) of this ICD-10 group. The next most common RIZIV/INAMI codification within this ICD-10 group is "Borderline Intellectual Functioning": 3% (NOK) and 6% (PSY). This means a good correspondence for 'Mild mental retardation' between the ICD-10 index classification and the RIZIV conventions.

ICD-10 Specific developmental disorders of speech and language

Within the ICD-10 index disorder "Specific developmental disorders of speech and language", the most common RIZIV/INAMI codification is 'Borderline Intellectual Functioning', accounting for 50% (NOK) and 61% (PSY) of this ICD-10 group. The next most common RIZIV/INAMI codification within this ICD-10 group is "Language developmental disorders": 25% (NOK) and 16% (PSY). This is followed by 'Mental retardation': 13% (NOK) and 17% (PSY)

ICD-10 Pervasive developmental disorders

Within the ICD-10 index disorder "Pervasive developmental disorders", the most common RIZIV/INAMI codification is 'Pervasive developmental disorders', accounting for 53% (NOK) and 53% (PSY) of this ICD-10 group. The next most common RIZIV/INAMI codification within this ICD-10 group is "Mental retardation": 19% (NOK) and 28% (PSY). This is followed by 'Borderline Intellectual Functioning': 15% (NOK) and 12% (PSY).

ICD-10 Hyperkinetic disorders

Within the ICD-10 index disorder "Hyperkinetic disorders", the most common RIZIV/INAMI codification is 'Hyperkinetic disorders', accounting for 52% (NOK) and 54% (PSY) of this ICD-10 group. The next most common RIZIV/INAMI codification within this ICD-10 group is "Borderline Intellectual Functioning": 17% (NOK) and 25% (PSY). This is followed by "Learning disorders": 18% (NOK) and 7% (PSY) as well as "Mental retardation": 5% (NOK) and 9% (PSY).

ICD-10 Conductive and sensorineural hearing loss

Within the NOK-specific ICD-10 index disorder "Conductive and sensorineural hearing loss", 95% is registered within the RIZIV/INAMI codifications for "Hearing disorders" (see Appendix 13 to chapter 2)

Key points

- **For 'Mild mental retardation' a good match exists between the RIZIV/INAMI conventions and the ICD-10 codes (91.7% in NOK and 91.8% in PSY) and for 'Conductive and sensorineural hearing loss' also (95% is registered with the RIZIV/INAMI codes 'Hearing disorders')**
- **Less good is the congruence (or "match") between the RIZIV/INAMI conventions and ICD-10-indexcodes by 'Specific developmental disorders of speech and language' ((24.7% in NOK and 16.1% in PSY), 'Pervasive developmental disorders'(53% in NOK and PSY), 'Hyperkinetic disorders'(54% in NOK and PSY) and 'Specific developmental disorders of scholastic skills'(65.5% in NOK and 53.7% in PSY)**

2.7.1.2 *RIZIV/INAMI conventions within the ICD-10 main index disorders: by language of the rehabilitation centres*

When considering patients with a specific ICD-10 code subdivided by NOK or PSY and at the same time by language, many subgroups become too small to allow for meaningful comparison of prevailing RIZIV/INAMI convention groups, especially in the French centres (see also Table 13 in section 2.4.1.8). Only two ICD-10 codes in the subdivision PSY-centres, namely "Mild mental retardation" and "Pervasive developmental disorders", comprise enough patients in Dutch as well as in French centres to allow for this comparison. More details can be found in the Appendix 13 to chapter 2.

For the patients in PSY centres with the ICD-10 index disorder 'Mild mental retardation', no large differences are perceived between their RIZIV/INAMI convention codifications in Dutch centres and in French centres.

Patients with 'pervasive developmental disorders' in the ICD-10 criteria are in Dutch PSY centres more often registered as having 'Infantile autism', Borderline intellectual functioning', and 'Atypical autism' in the RIZV/INAMI conventions than the patients in the French speaking centres. In French speaking centres patients with 'Pervasive developmental disorders' in the ICD-10 criteria are more often registered as having 'Mental Retardation" and 'Pervasive developmental disorders' than the patients in Dutch speaking centres. For the ICD-10 diagnosis of 'Pervasive developmental disorders' it seems reasonable to take the RIZIV/INAMI categories 'Infantile autism', 'Pervasive developmental disorders' and 'Atypical autism' together, especially since the coding has been done by many different persons, allowing for subtle differences in interpretation.

2.7.2 ICD-10 main index disorders within RIZIV/INAMI conventions

As already pointed out, in this paragraph the participants in the data sample belonging to a specific ICD-10 category and at the same time to a specific RIZIV/INAMI convention disorder are presented as a percentage of the total RIZIV/INAMI convention disorder (see row C in Table30-B). More detailed tables can be found in Appendix 13 to chapter 2, including detailed data on subdivision by language.

RIZIV/INAMI disorder "Mental retardation"

Within the RIZIV/INAMI disorder "Mental retardation", the most common ICD-10 index disorder is 'Mild mental retardation', accounting for 59% (NOK) and 49% (PSY) of this RIZIV/INAMI group. The ICD-10 index disorder 'Mild mental retardation' accounts for 64% of the RIZIV/INAMI disorder "Mental retardation" in Dutch NOK/PSY centres and for 34% in French NOK/PSY centres. It should be noted that moderate, severe and profound mental retardation are uncommon ICD-10 codes (4.95%).

The next most common ICD-10 codification within this RIZIV/INAMI group is "Pervasive developmental disorders": 8% (NOK) and 10% (PSY). This is followed by "Specific developmental disorders of speech and language": 10% (NOK) and 4% (PSY).

RIZIV/INAMI disorder "Borderline intellectual functioning"

For this paragraph, it should be kept in mind that the category 'Borderline intellectual functioning' can not be coded in the ICD-10 classification as a disorder as such (see 2.8.1).

Within the RIZIV/INAMI disorder "Borderline intellectual functioning", the most common ICD-10 index disorder is 'Specific developmental disorders of speech and language', accounting for 35% (NOK) and 26% (PSY) of this RIZIV/INAMI group. The next most common ICD-10 codification within this RIZIV/INAMI group is "Specific developmental disorders of scholastic skills": 26% (NOK) and 15% (PSY). This is followed by "Hyperkinetic disorders": 9% (NOK) and 10% (PSY).

RIZIV/INAMI disorder "Learning disorders"

Within the RIZIV/INAMI disorder "Learning disorders", the most common ICD-10 index disorder is 'Specific developmental disorders of scholastic skills', accounting for 77% (NOK) and 72% (PSY) of this RIZIV/INAMI group. The next most common ICD-10 codification within this RIZIV/INAMI group is "Hyperkinetic disorders": 10% (NOK) and 9% (PSY).

Key points

- **For the RIZIV/INAMI convention subgroup 'Mental retardation', 41% (NOK) and 51% (PSY) of the patients had another diagnostic ICD-10 code**
- **For this RIZIV/INAMI subgroup, the correspondence with the ICD-10 "Mild mental retardation" is higher in Dutch speaking NOK/PSY centres (64%) than in French NOK/PSY centres (34%).**
- **For the RIZIV/INAMI convention subgroup "Borderline intellectual functioning", for which no direct ICD-10 codification exists, the most frequent ICD-10 codes are 'Specific developmental disorders of speech and language' (35% in NOK; 26% in PSY) and "Specific developmental disorders of scholastic skills" (26% in NOK; 15% in PSY)**
- **For the RIZIV/INAMI convention subgroup 'Learning disorders', about 23% and 28% of the patients had another diagnostic ICD-10 code.**

Table 30-B: Five most frequent index ICD-10 categories, combined with five most frequent RIZIV/INAMI convention disorders

						ICD-10			ICD-10			ICD-10			ICD-10			ICD-10			
						Mild mental retardation			Specific developmental disorders of speech			Pervasive developmental disorders			Specific developmental disorders of			Hyperkinetic disorders			
					NOK	343			406			223			603			299			
					PSY	527			255			362			271			245			
					Total(*)	870			661			585			874			544			
		NOK	PSY	Total (**)		NOK	PSY	Total (***)	NOK	PSY	Total (***)	NOK	PSY	Total (***)	NOK	PSY	Total (***)	NOK	PSY	Total (***)	Total (****)
RIZIV - INAMI	Mental retardation	525	984	1509	A	309	483	792	52	42	94	42	100	142	13	16	29	14	22	36	1093
					B	91%	92%	91%	13%	17%	14%	19%	28%	24%	2%	6%	3%	5%	9%	7%	
					C	59%	49%	52%	10%	4%	6%	8%	10%	9%	3%	2%	2%	3%	2%	2%	
RIZIV - INAMI	Learning disorders	500	201	701	A	0	1	1	15	9	24	12	9	21	383	145	528	50	17	67	641
					B	-%	-%	-%	4%	4%	4%	6%	3%	4%	65%	54%	60%	18%	7%	12%	
					C	-%	-%	-%	3%	5%	3%	2%	5%	3%	77%	72%	75%	10%	9%	10%	
RIZIV - INAMI	Borderline intellectual functioning (harmonic/ non-harmonic profile)	580	598	1178	A	11	29	40	205	156	361	33	42	75	151	91	242	51	61	112	830
					B	3%	6%	5%	50%	61%	55%	15%	12%	13%	25%	34%	28%	17%	25%	21%	
					C	2%	5%	3%	35%	26%	31%	6%	7%	6%	26%	15%	21%	9%	10%	10%	
RIZIV - INAMI	Language developmental disorders	138	52	190	A	6	low		97	41	138	7	low		5	low		7	low		
					B	2%	-%		25%	16%	21%	3%	-%		1%	-%		3%	-%		
					C																
RIZIV - INAMI	Hyperkinetic disorders	209	158	367	A	low	low		5	low		low	6		25	9	34	156	133	289	
					B	-%	-%		1%	-%		-%	2%		4%	3%	4%	52%	54%	53%	
					C																

RIZIV - INAMI	Pervasive developmental disorders	129	135	264	A	low	low		low	low		116	193	309	low	low		low	low				
					B	-%	-%		-%	-%		52%	53%	53%	-%	-%		-%	-%				
					C																		
				Total		337	526		393	254		218	362		585	270		285	244				

Total(*): N participants in data sample for whom a specific ICD-10 codification is available
Total(**): N participants in data sample for whom a specific RIZIV-INAMI codification is available
Total(***): N participants in data sample for whom both a specific ICD-10 and a specific RIZIV-INAMI codification is available
Total(****): N participants within all five most frequent ICD-10 codifications, for whom a specific RIZIV-INAMI codification is available
A: N participants with the ICD-10 as well as the RIZIV-INAMI codification
B: N is X% of total (NOK respectively PSY) ICD-10 category
C: N is Y% of total (NOK respectively PSY) RIZIV/INAMI category
low: less than 5 participants

2.8 THE ASSOCIATED DISORDER 'R418'

2.8.1 Introduction

In the ICD-10, the RIZIV/INAMI category 'Borderline intellectual functioning' (IQ range from 70 to 84) is not considered as a psychological or a conduct disorder but belongs to 'other signs and unspecified symptoms and signs involving cognitive functions and awareness'. The registration procedure in the Dutch speaking centres demanded to register it as an associated disorder with the ICD-10 code 'R418' (the ICD-10 item[s] referred to in the DSM-IV for 'borderline intellectual functioning'[t]). In this section, extra analyses of this associated disorder were made.

2.8.2 Age and sex within R418

From the 3658 patients in Dutch speaking rehabilitation centres in the sample, 819 (22.4%) have the associated disorder 'R418 - Other and unspecified symptoms and signs involving cognitive functions and awareness' with an age range of 1 to 17 years (mean 8 years 9 months, SD 2 years 3 months) and a male/female ratio of 1.7/1.

2.8.3 NOK or PSY, province and official language of the rehabilitation centres within R418

From the 819 patients with R418 as an associated disorder, 449 patients (54.8%) are going to Dutch speaking NOK centres, the others go to Dutch speaking PSY centres. In Table 30, an overview of the provinces of the Dutch speaking rehabilitation centres with patients with R418 as an associated disorder is presented. As abovementioned, 'Brabant' contains all Dutch speaking rehabilitation centres situated in Flemish Brabant, Walloon Brabant and Brussels.

Table 30: Provinces of the Dutch speaking rehabilitation centres with patients with R418 as an associated disorder

Province	N	% within R418	% within the cases in the province
Antwerp	9	1.1	9.7
Brabant	45	5.5	12.6
West-Flanders	168	20.5	16.5
East-Flanders	561	68.5	24.9
Limburg	36	4.4	20.1
Total	819	100	

2.8.4 Educational level within R418

Most of the patients with R418 as an associated disorder are going to primary education (52.4%) and preschool (33.0%). From the patients who are going to school, 12.9% are in special education. Descriptive information for the sample is presented in Table 31 This seems not different as compared to the general educational level in the Dutch speaking rehabilitation centres (see Table 30).

s R41.8 ('other and unspecified symptoms and signs involving cognitive functions and awareness') (www.who.int/classifications/apps)

t V62.89 ('additional problems as reason for care:': 'Borderline intellectual functioning')

Table 31: Educational level of patients with R418 as an associated disorder in Dutch rehabilitation centres

Educational level	N	%
Not going to school	7	0.9
Preschool	266	33.0
Preschool, special education	3	0.4
Primary education	422	52.4
Special primary education	94	11.7
Secondary education	6	0.7
Special secondary education	6	0.7
Technical and vocational training	1	0.1
Total	805	100
Missing cases	14	

2.8.5 ICD-10 Index disorders within R418

In Table 32, an overview is provided of the index disorders within the associated disorder R418, showing that 'Specific developmental disorders of speech and language' (32.2%) and 'Specific developmental disorders of scholastic skills' (21.5%) are most prevalent but, other index disorders are also common. This leads to the conclusion that R418 can go together with a variety of different index disorders.

Table 32: Index disorders within R418

Index disorders	N	%
F81 Specific developmental disorders of scholastic skills	176	21.5
F70 Mild mental retardation	3	0.4
F80 Specific developmental disorders of speech and language	264	32.2
F84 Pervasive developmental disorders	82	10.0
F90 Hyperkinetic disorders	95	11.6
H90 Conductive and sensorineural hearing loss	1	0.1
F82 Specific developmental disorders of motor function	90	11.0
Z0321 No diagnose	35	4.3
F98 Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence	23	2.8
Total	769	93.9

2.8.6 ICD-10 Co-morbid disorders within R418

From the 819 patients with R418 as an associated disorder, 338 patients (41.3%) have no co-morbid disorders, 313 patients (38.2%) had 1 co-morbid disorder, 135 patients (16.5%) had 2 co-morbid disorders and 33 patients (4.0%) had 3 co-morbid disorders. In Appendix 14 to chapter 2, an overview is presented of the co-morbid disorders within patients with R418 as an associated disorder.

Table 33: Co-morbid disorders within R418

Co-morbid disorders	N	%
F80 Specific developmental disorders of speech and language	181	22.1
F82 Specific developmental disorder of motor function	156	19.0
F81 Specific developmental disorders of scholastic skills	84	10.3
F90 Hyperkinetic disorders	87	10.6
F98 Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence	29	3.5
F84 Pervasive developmental disorders	29	3.5
Total	566	69.1%

(Note that the abovementioned co-morbidities do not involve unique persons since one patient can have several comorbidities).

2.8.7 Complaint by registration within R418

In Appendix 14 to chapter 2, an overview is presented of the complaints by registration within the (Dutch) patients with R418 as an associated disorder, showing that 'Developmental retardation' (35.5%) and 'Language/speech problems' (21.2%) are most prevalent complaints by registration within this group.

2.8.8 RIZIV/INAMI conventions within R418

The most common disorder in RIZIV/INAMI conventions in patients with R41.8 as an ICD-10 associated disorder is 'Borderline intellectual functioning' (79% in NOK centres and 77% in PSY centres). It is remarkable that 33 patients (7.4%, NOK centres) respectively 28 patients (7.6%, PSY centres) have 'Mental retardation' as disorder in RIZIV/INAMI convention, together with R418 as an associated disorder. This may be due to a registration error, but it is not excluded that 'Mental retardation' was preferred since this is a RIZIV/INAMI category providing a longer period of therapy in rehabilitation centres.

More details can be found in the Appendix 14 to chapter 2.

Key points

- **The main index disorders 'Specific developmental disorders of speech and language' and 'Specific developmental disorders of scholastic skills' are most prevalent within the associated disorder R418 (respectively 32.2% and 21.5%). 'Hyperkinetic disorders', 'specific developmental disorders of motor function' and 'Pervasive development disorders' counted each for about 10%.**
- **The most prevalent co-morbid disorders within R418 are 'Specific developmental disorders of speech and language (22.1%) and 'Specific developmental disorder of motor function' (19%)**
- **Within the patients with R418 as an associated disorder in the NOK and the PSY rehabilitation centres, the most common RIZIV/INAMI category is 'Borderline intellectual functioning (respectively 79% and 77%), followed by 'Mental retardation' (respectively 7.4% and 7.6%).**

2.9 CONCLUDING REMARKS AND DISCUSSION

2.9.1 NOK/PSY population: general information

General information on the NOK/PSY population in the sample revealed that adults comprise only 2.5% of the population. Further, 71 % belongs to the age group 6-11 years (and especially 7-10 years), whereas infants and toddlers (0-5 years) account for 8.4%. Especially in children with "conductive and sensorineural hearing disorders" or, to a lesser degree, "mild mental retardation" as an index disorder, therapy is started at a younger age. For learning disorders, which is the main index diagnosis for 18% of the population according to the ICD-10 codification (20% respectively 8% in NOK respectively PSY centres for RIZIV/INAMI codifications), this age distribution seems reasonable, but it is less obvious for other diagnostic categories, e.g. for speech- and language disorders, or e.g. for pervasive developmental disorders for which the literature review insists on early treatment. Maybe some of these children appeal to other therapeutic options e.g. supporting care at home or special education.

The information from the Dutch rehabilitation centres taught that only 15% of participants follow special education. This is comparable to data of the RIZIV/INAMI-study on NOK/PSY centres (RIZIV/INAMI, 2003), and takes the edge of the former viewpoint that NOK/PSY centres mostly treat children from special education. Nevertheless, one should remain critical; and for every child but especially for children that are already involved in another system providing special support, it is essential to clearly define at the beginning of the rehabilitation therapy the added value that potentially can be created.

2.9.2 NOK/PSY population: complaints by registration

Information on the complaints by registration is available for the Dutch speaking centres. Only for developmental disorders of scholastic skills and for conductive and sensorineural hearing loss, the main complaint matches the exact diagnosis in more than 50% of the cases. Other complaints by registration are very diverse. The analysis of the RIZIV/INAMI codes within the different complaints by registration, yields similar results, and also highlights the importance of the diagnostic process in the rehabilitation centres.

2.9.3 NOK/PSY population: diagnostic categories

2.9.3.1 Disorders in RIZIV/INAMI conventions

In the study sample, participants were classified according to their RIZIV/INAMI encoding. NOK and PSY centres are mentioned separately because, although largely overlapping, some convention categories exist in NOK but not in PSY centres and vice versa.

The most prevalent disorders in RIZIV/INAMI conventions for NOK respectively PSY centres can be found in Table 28 and Table 29 (see 2.5.1). Although the three most important disorders in RIZIV/INAMI categories (mental retardation, borderline intellectual functioning, learning disorders) are the same for NOK and PSY centres, mental retardation is much more common in PSY centres (41%) than in NOK centres (21%); and learning disorders are more common in NOK centres (20%) than in PSY centres (8%). The next two most common disorders are more typical of NOK respectively PSY centres: hearing disorders is the 4th most prevalent category in NOK (12%) and pervasive developmental disorders the 5th most prevalent in PSY (6%). It can be concluded that some differentiation exists between the patient population in RIZIV/INAMI conventions in NOK and PSY centres; but the difference is not large.

2.9.3.2 ICD-10 classification

Typical of the ICD-10 as one of the main internationally accepted, WHO-endorsed classification systems for diseases[u], is that it allows for codification according to well-described criteria. In the ICD-10 classification it is recommended that "clinicians should follow the general rule of recording as many diagnoses as necessary to cover the clinical picture", by indicating the main condition and other conditions (also called associated conditions) (ICD-10 Bluebook, p12).

Main ICD-10 index disorders

Taken NOK/PSY centres together, the most important main index disorders are 'Mild mental retardation' (17.7%) and 'Developmental disorders of scholastic skills' (17,8%); followed by 'Developmental disorders of speech and language' (13,5%), 'Pervasive developmental disorders' (11,9%), 'Hyperkinetic disorders' (11,1%), and finally 'Conductive and Sensorineural Hearing Loss' (5.7%). Generally 4338 of the 4907 patients (88.4%) in the sample are explained by the three clusters 'Mental retardation', 'Developmental disorders' and 'Behavioural disorders' (see Table 17 and Appendix 4 to chapter 2).

As to the difference between NOK and PSY centres, the two most important main index disorders, 'Mild mental retardation' and 'Developmental disorders of Scholastic skills', belong to the three most important main index disorders in NOK as well as in PSY; but 'Mild mental retardation' is more common in PSY (14% NOK, 22% PSY) whereas 'Developmental disorders of Scholastic skills' is more common in NOK (24% NOK, 11% PSY). Further, 'Developmental disorders of speech and language' belongs to the three most important main index disorders in NOK (16%), whereas 'Pervasive developmental disorders' belongs to the three most important main index disorders in PSY (15%). This confirms that there are some differences in patient population between NOK and PSY centres. The five most important main index disorders in NOK respectively PSY centres, amount to 75% respectively 69%, when taken into account

u http://www.who.int/classifications/icd/en/ (access date 11-9-08)

that 'Conductive and sensorineural hearing loss' cannot be treated in PSY centres. In other words, overall differences are not very large (see Table 22).

ICD-10 Comorbidities

The three most prevalent comorbidities for all index disorders together are: 'Developmental disorders of speech and language' (24.8%), 'Developmental disorder of motor function' (18.1%) and 'Developmental disorders od scholastic skills' (15.2%). They are followed by 'Hyperkinetic disorders' (11.3%), 'Other behavioural and emotional disorders' (5.6%) and 'Pervasive developmental disorders (5.5%). 'Mild mental retardation' is only a comorbidity in 4.6% of clients; the combination of mild, moderate, severe and profound mental retardation accounts for 6.9% of the co-morbidities (see Table 17).

It is clear, that a large overlap exists between the 6 most prevalent main index disorders and the 6 most prevalent co-morbidities. Indeed, 4 of the 6 most prevalent disorders are the same in the main index disorders and the co-morbidities ('Developmental disorders of Scholastic skills', 'Developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'). Important main index disorders that are not an important comorbidity are 'Mild mental retardation' and 'Conductive and Sensorineural Hearing Loss'. Important comorbidities that are not an important main index disorder are 'Specific developmental disorder of motor function' and 'Other behavioural an emotional disorders with onset usually occurring in childhood and adolescence'.

The three most important co-morbidities for all index disorders together are largely the same as the three most important co-morbidities for each of the 6 main index disorders separately, although in a different order for each different main index disorder.

The same three most prevalent co-morbidities ('Developmental disorders of speech and language'; 'Specific developmental disorder of motor function'; 'Developmental disorders of Scholastic skills') are also the three most prevalent co-morbidities within NOK-centres as well as within PSY centres, and even the six most frequent co-morbidities are the same in NOK centres and in PSY centres. However, in NOK centres they account for 92.4% of co-morbidities, whereas in PSY centres they only account for 59.7%. The next most frequent co-morbidities (7th, 8th…) in PSY centres are diverse and all of a low prevalence.

A methodological point concerning the registration of co-morbid disorders is that strictly speaking when applying the ICD-10 rules, the diagnosis "developmental disorder of scholastic skills", or "developmental disorder of speech and language" requires 4 main criteria. Severity is one of these, requiring a functioning outside the limits of 2 standard deviations, or below the 3rd percentile for language or scholastic skills as compared to the general level of cognitive functioning of the person. A typical course and pattern are also required. The fourth requirement is the presence of "many associated problems like abnormalities in interpersonal relationships, behavioural disturbances, scholastic deficits" (see ICD Bluebook [v], p183). Strictly speaking, comorbidities and associated disorders, as defined in this study, are necessarily part of the main index disorder for "developmental disorder of scholastic skills", or a "developmental disorder of speech and language". Consequently, to judge on the significance of co-morbidities for the patients treated in NOK/PSYcentres, a comparison with the prevalence of co-morbidities for the same children treated outside NOK/PSY centres is necessary.

ICD-10 Associated disorders

The most frequent associated problem taken all main index disorders together was 'Other signs and symptoms involving cognitive functions and awareness' (see Table 17). Since 'Bordeline intellectual functioning' (TIQ 70-84) is not defined as a disorder in ICD-10, this codification was used in Dutch speaking centres, according to its reference in DSM-IV. In Dutch centres, it accounted for 22,4%. The next most frequent associated

[v] www.who.int

problems were 'Problems relating to upbringing' or 'Problems relating to primary support group (including family circumstances)' (Z-codes in the ICD-10 classification), which accounted together for 17.6% of the associated disorders, more frequently codified in French speaking centres (see Appendix 5 to Chapter 2).

For each of the 6 most prevalent main index disorders the same associated disorders, always in the same order, are the most important associated disorders. The only exception is 'Conductive and Sensorineural Hearing Loss', where a different kind of associated disorders is found, specifically related to hearing problems.

For the associated disorders a higher percentage of Z-codes was found in PSY centres than in NOK centres, as expected (see Appendix 5 to chapter 2).

Number of comorbidities and associated disorders

In the six most prevalent main index disorders of the study sample, 30% resp. 18% resp. 7% had 1 resp. 2 resp. 3 comorbidies, and about 35% resp. 10% had 1 resp. 2 associated disorders. On the other hand, 23% in the main index categories did not have any comorbidity. An exception was "Conductive and sensorineural hearing loss": 45% had no comorbidities; but in this category (as well as in Developmental Disorders of speech and language), associated disorders were somewhat more common. Finally, roughly 10% of participants in the main index categories did not have any comorbidity or associated disorder (see Appendix 6 to chapter 2). This percentage was +- evenly distributed across all main diagnostic categories; only for "Developmental Disorders of speech and language" it was somewhat lower, and for 'Developmental disorders of Scholastic skills' it was higher (17.6%) since 64.1% of these disorders are 'mixed', i.e. co-morbid.

2.9.3.3 Comparison of RIZIV/INAMI codifications and ICD-10 codifications

General considerations

The ICD-10 is an international standard diagnostic classification for epidemiological and health management purposes e.g. studying the incidence and prevalence of diseases and in relation to other variables such as the characteristics and circumstances of the individuals affected, reimbursement, resource allocation, quality and guidelines[w]. Hence it provides professionals with clear definitions so that they use the same concept for the same type of problems. In the ICD-10 classification comorbidities and associated disorders are allowed, and they are also clearly defined which helps to refine the diagnosis and also makes diagnostic data on patients more comparable across different settings.

The RIZIV/INAMI codification also refers to the ICD-classification for definitions of many categories (see Appendix to Chapter 1). On the other hand, in the RIZIV/INAMI codification there are also some important differences and there is a separate category for 'Borderline intellectual functioning' (i.e. TIQ range 84-70) which is not included as a disorder in ICD-10 (in the Dutch speaking centres this problem was solved by registering the ICD-10 item[x] related with the DSM-IV code for this condition[y] as an associated disorder). At least for the Dutch speaking centres, 'Borderline intellectual functioning' was the most important associated problem, accounting for 22%. Comorbidities and associated disorders are not included in the RIZIV/INAMI codification.

Comparison of the 2 codification systems within the database

A. Comparison of the type of disorders in the 2 codification systems

The direct comparison of the disorders that appeared in the classification by the 2 codification systems indicates that the RIZIV/INAMI codifications and ICD-10 codifications largely concern the same groups of disorders: the six most important ICD-10 main index disorders have an equivalent in the RIZIV/INAMI convention system.

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w www.who.int

x R41.8 ('other and unspecified symptoms and signs involving cognitive functions and awareness') (www.who.int/classifications/apps)

y V62.89 ('additional problems as reason for care:': 'Borderline intellectual functioning')

Sometimes there is a direct referral (as for most categories of "Pervasive developmental disorders"), sometimes the descriptions are variations of ICD-10 criteria

(as for 'Developmental disorders of speech and language', 'Developmental disorders of Scholastic skills', 'Hyperkinetic disorders', 'Mild mental retardation').

Three groups of the main ICD-10 index disorders cannot be codified directly in the RIZIV/INAMI system: 'Developmental disorder of motor function', (accounting for 3.6% as an index and for 18.0% as a co-morbid disorder), 'Moderate mental retardation' (3.7% as an index disorder; although they can be classified in the RIZIV/INAMI system as 'Mental retardation', the difference between mild and moderate mental retardation is lost)[z] and 'Other behavioural and emotional disorders with usual onset in childhood' (co-morbidity for 5.6% of participants), a combination of different disorders that are not otherwise specified.

As to the associated aspects, 'Problems related to upbringing' and 'Problems related to primary support group, including family circumstances' (ICD-10 Z-codes), accounting together for 17.6 % of associated disorders, can not be codified in the RIZV/INAMI classification. On the other hand there is a RIZIV/INAMI-group "Borderline intellectual functioning" that has no counterpart in de ICD-10 classification of disorders (see earlier).

We can conclude that the RIZIV/INAMI-classification is based on the ICD-10, but that there are also, sometimes major, differences between them.

B. Comparison of the ICD-10 main index disorders with the corresponding RIZIV/INAMI codifications

In Table 30-B, we can see the correspondence between ICD-10 codes and RIZIV/INAMI categories. The correspondence between the main index ICD-10 codification 'Mild mental retardation' or 'Conductive and Sensorineural Hearing Loss' and the RIZIV/INAMI codification 'Mental retardation' is very high (>91,7% in NOK and 91.8% in PSY centres) and this is also the case for 'Hearing loss' (93.5%).

For the ICD-10 code 'Developmental disorders of Scholastic skills', the correspondence with the RIZIV/INAMI codification is 53.7% (PSY) to 65.5% (NOK). This raises to nearly 90% taken into account that children with learning disorders and a TIQ within the range 70-84 were RIZIV-coded as 'Borderline intellectual function'. This could be the case due to reimbursement advantages[aa]. Still then, 10% remains unexplained.

For 'Pervasive developmental disorders', there is a correspondence of 53% between the 2 codification systems. Though the RIZIV/INAMI codification 'Borderline intellectual functioning' differs fundamentally from the core problems of children with 'Pervasive developmental disorders' and offers little reimbursement advantage (1 year), it accounts for 11.6 to 14.2%. Possibly this category was taken as an alternative on behalf of the family or as a provisional diagnostic label. So, 32 to 35% of the RIZIV/INAMI codifications for the main index ICD-10 codification 'Pervasive developmental disorders' remain unexplained. It is remarkable that a large part of this is taken by the RIZIV/INAMI codification 'Mental retardation' (19.3 to 27.6%), especially since the correspondence between ICD-codification and RIZIV/INAMI codification for 'Mental retardation' is very high. Also, the ICD-codification 'Mental retardation' accounts only for 6.85% of all co-morbidities, so a simple swab between the ICD-10 index disorder and the ICD-10 co-morbid disorder cannot explain this finding. The difference is also too large to be only caused by codification errors. Possibly, also here reimbursement advantages may play a role (6x1 year instead of 3x1 year) possibly corresponding to the opinion of some caregivers that 'Pervasive developmental disorders' deserves more that 3 years of rehabilitation.

For 'Hyperkinetic disorders' the situation is comparable to 'Pervasive developmental disorders', but to a lesser degree. The direct correspondence between the 2 codification systems is only 54%, and the RIZIV/INAMI codification 'Borderline intellectual functioning' accounts for 17.9 to 25.0%, what can be explained the same way

z This is the same for severe (0.7%) and profound (0.6%) mental retardation.

aa These children will then have a maximum period of 4 years rehabilitation instead of 2

as previous. This implies that 20 to 27% of the RIZIV/INAMI codifications for the main index ICD-10 codification 'Hyperkinetic disorders' remains unexplained.

Here, the RIZIV/INAMI codification 'Mental retardation' takes 4.9 to 9.0%, and might be partially explained by a swab between ICD-main index disorder and co-morbidity, despite the low categorical correspondence.

The RIZIV/INAMI codification 'Learning disorders' takes 17.5% respectively 7.0%. The ICD-10 code 'Developmental disorders of Scholastic skills' accounts for 15.2% of all co-morbidities, so a possible explanation can be that first, patients with a hyperkinetic disorder are treated under this RIZIV/INAMI codification and that later on, the same patients get a treatment under the RIZIV/INAMI codification of (one of) their co-morbid disorder(s). Still, a small percentage of these codifications is difficult to understand, and is possibly related to codification errors.

For 'Developmental disorders of speech and language', the direct correspondence between the main index ICD-10 codification and the RIZIV/INAMI codification is very low, and accounts for only 16.1 to 24.7%. The RIZIV/INAMI codification 'Borderline intellectual functioning' accounts for 61.4 respectively 52.5% within this ICD-codification. This implies that 23% of the RIZIV/INAMI codifications for the main index ICD-10 codification 'Developmental disorders of speech and language' remain unexplained. Again, a large percentage of this is taken by the RIZIV/INAMI codification 'Mental retardation': 13.2 to 16.5%. The same remarks can be made as for pervasive developmental disorders.

When the reverse exercise is made, i.e. when the different main index ICD-10 codifications within one RIZIV/INAMI codification are evaluated, the above findings seem to be confirmed (table 30-B). Within the RIZIV/INAMI codification 'Mental retardation', 71.0 to 72.8% of the patients has the same ICD-10 main index codification, and a large part is taken by 'Pervasive developmental disorders' (10.0 to 15.1%) and 'Developmental disorders of speech and language (11.9 respectively 6.4%). Within the RIZIV/INAMI codification 'Learning disorder', 80.1 to 83.0% of the patients have the right corresponding ICD-10 main index codification and 9.4 to 10.8 % is found under the ICD-10 main index codification 'Hyperkinetic disorders'. The RIZIV/INAMI codification 'Borderline intellectual functioning' seems to be taken over largely by 'Developmental disorders of speech and language' in the main index ICD-10 codifications, but also by 'Developmental disorders of Scholastic skills' and 'Hyperkinetic disorders' (e.g. 'Borderline intellectual functioning with harmonic profile' is replaced by 'Developmental disorders of speech and language' in 38.1 respectively 47.1%).

In conclusion, for some diagnostic categories, namely 'Mild mental retardation' and 'Conductive and Sensorineural Hearing Loss', a very good correspondence exists between the ICD-10 codification and the RIZIV/INAMI codification. For other categories, this is less the case, even when taken into account that the RIZIV/INAMI codification 'Borderline intellectual functioning' can explain certain discordances.

This "mismatch" is not easy to evaluate, and it is likely that many reasons help to explain this phenomenon. In case of co-morbidities, it is not excluded that the rehabilitation centres first treat the client in the RIZIV/INAMI category of their index disorder, and later on in the category of their co-morbidities ("swabbing") to adjust the maximum duration of reimbursed rehabilitation to the needs of particular patients. Indeed, a large overlap exists between the most frequent ICD-10 index disorders and the most frequent co-morbidities. Another hypothesis is that reimbursement periods can be upgraded by allocating the patient in more favourable RIZIV/INAMI groups. For instance, it is remarkable that the "alternative" RIZIV/INAMI codification often is 'Mental retardation', which is only rarely a co-morbidity in the ICD-10 codes (6.85%, see Table 17) but is the most favourable RIZIV/INAMI codification from the point of view of the reimbursement scheme. Since this is not the case for all diagnostic categories, namely not for 'Developmental disorders of Scholastic skills', a hypothesis can be that this "upgrading" takes only place for those categories where the caregivers feel that the available convention therapy duration is not sufficient.

2.9.3.4 *Is there a difference in patient population between NOK and PSY centres?*

From the previous, it is clear that the diagnostic categories treated in NOK respectively PSY centres are largely the same. With the exception of the category 'Conductive and Sensorineural Hearing Loss', which can only be treated in NOK centres, only the frequency of certain diagnoses is different between the 2 types of centres, and shows a certain specialization in line with the expected differentiation between the two types of centres. This is true for the main index diagnostic categories (ICD-10) as well as for the RIZIV/INAMI classification; this is also true for the co-morbidities and associated disorders. It should be noted that the diagnostic categories that are exclusively assigned to PSY centres (e.g. schizophrenia, bipolar disorders, see Appendix to Chapter 1), seem to be infrequent.

An exception on many similarities between all the other diagnostic categories, is 'Conductive and Sensorineural Hearing Loss', which can only be treated in NOK centres. Patients in this diagnostic categories start more often at a younger age than in other diagnostic categories. Also, the co-morbidities for this diagnostic category are less frequent, and associated disorders are somewhat more frequent and are specific for patients with hearing loss. Finally, the provided disciplines are different as compared to the other diagnostic categories (information from Dutch centres only), and mainly speech therapists and audiologists are involved.

2.9.3.5 *Is there a difference in patient population between Dutch and French speaking rehabilitation centres?*

With the remark that the French NOK centres might not be fully representative, there are to mention some differences between the diagnostic codifications in the Dutch and the French rehabilitation centres. The six most prevalent main index disorders (see Table 21) account for 83.9% of the main index disorders in Dutch speaking centres, and only for 59.7% in French speaking centres. The most striking example is the diagnosis 'Developmental disorders of Scholastic skills', which is frequent in Dutch centres (21.8% of all main index disorders) but less in French centres (6.1%). Next to the six most important index disorders for all centres together, the most frequent index disorders in French speaking centres are 'Moderate mental retardation' (7.2%), 'Mixed specific developmental disorders' (4.6%), 'Disorders of social functioning' (4.1%) and 'Cerebral palsy' (3.4%).

When comparing main index disorders for Dutch and French NOK respectively PSY centres (see Appendix 5 to Chapter 2), the numbers of participants in one diagnostic category (especially in the French centres) became too small to judge on differences. Moreover, the database sample might not be fully representative for the French NOK centres. On the other hand, when comparing Dutch and French PSY centres within the RIZIV/INAMI codifications (Table 30), the difference for 'Learning disorders' could be confirmed (13% respectively 0.6%), but also 'Hyperkinetic disorders' appeared to be more frequent in Dutch PSY centres (9.7% respectively 1.4%). 'Mental retardation' appeared to be more frequent in French PSY centres (34% respectively 54%). Concerning co-morbidities, differences in Dutch and French centres are less clear. Associated disorders were diverse, and were not further compared between Dutch and French centres.

Why the main index diagnostic categories are different in Dutch and French speaking centres, is not clear. It might be due to differences in medical schools between the two languages. It can also be that the patient population that presents to the French NOK/PSY centres is different from the Dutch patient population, because prevalence rates of certain disorders are different, or because other services that provide care for the same patient population (e.g. special education) are less prevalent or further away, so that parents prefer more nearby services (see also Chapter 1)

3 LITERATURE EVIDENCE

3.1.1 Introduction

The objective of the literature search was to review the evidence concerning interventions for disorders that are treated in Belgian NOK and PSY rehabilitation centres.

In our research (see Chapter 3 Data analysis) a high prevalence of the following ICD-10 codes registered within rehabilitation centres was discovered:, 'Specific developmental disorders of scholastic skills' (F81), 'Mild mental retardation' (F70), 'Specific developmental disorders of speech and language' (F80), 'Pervasive developmental disorders' (F84) and 'Hyperkinetic disorders' (F90). As a result, the objective of this literature search became the description of the most relevant evidence-based treatment methods concerning these disorders. Due to time restrictions 'Mild mental retardation' will not be included separately in our literature-part of this report. However it will be included implicitly because 'it occurs together with 'Specific developmental disorder of scholastic skills', 'Specific developmental disorder of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorder'. These comorbidities make it difficult to provide specific treatment methods for this disorder. Treatment will focus on difficulties that these children experience in scholastic skills, speech and language difficulties … and therefore are included implicitly in the literature concerning abovementioned disorders. In addition to this, people with mental retardation are commonly treated within special education and less commonly in rehabilitation centres. All these abovementioned reasons lead to the conclusion to exclude 'mild mental retardation', as a separate part, in the literature study.

3.1.2 Methodology

The following databases were explored using well described keywords and thesaurus: 'Medline', 'Embase', 'PsycInfo', 'Cochrane', 'Web of Science', 'Eric', 'PEDro' and 'CIRRIE'. Consulted articles were published between January 1997 and December 2007, since the evolution in the practical field has been large for the last 10 years. Research questions were based on PICO (patient, intervention, comparison and outcome) and involved evidence-based treatment methods for 'specific developmental disorders of speech and language', for 'specific developmental disorders of scholastic skills', for 'pervasive developmental disorders' and for 'hyperkinetic disorders'. For each research question and for each database the used keywords and search strategies are presented in the 'search strategy table' (see Appendix to Chapter 3). Next, for each research question a 'flow' (see Appendix to Chapter 3) was used. For 'specific developmental disorders of speech and language' and for 'specific developmental disorders of scholastic skills', the used keywords and search strategies and consequently also the flow, are generated together to avoid overlap. However both disorders are discussed separately in the review. The retained number of qualified studies, based on title and abstract, are reported, according to well-defined in- and exclusion criteria. For these potentially appropriate studies, the full text was evaluated.

Systematic reviews, meta-analyses and randomized controlled trials had to meet the Cochrane quality criteria (see Appendix to Chapter 3). For the HTA-reports, INAHTA-criteria[bb] were used (see Appendix to Chapter 3). Quasi-experimental studies were judged through Cochrane quality criteria for randomized controlled trials[cc]. Because generalisation of single-subject studies remains problematic, especially when studying disorders or pathological situations instead of healthy volunteers, and because this report aims to advise the government based on well-established conclusions, about topics concerning groups of patients rather than few individual cases, it was decided to exclude single-subject studies. When experimental and quasi-experimental studies did not meet the criteria of Cochrane, they were evaluated according to the quality criteria described by Gersten and colleagues (see Appendix to Chapter 3) [9].

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cc http://www.cochrane.org

The quality indicators described by Gersten and colleagues were generated for special education settings. The indicators not only intended to evaluate the merits of a completed research report or article but they also intended to serve as an organizer of critical issues for consideration in research. It is a standard for determining whether or not an educational practice may be considered evidence-based. This method was chosen because it is complementary to the Cochrane criteria.

The following criteria, considered by the working group are also used to exclude studies from appraisal: studies that:

- reported pure pharmacological, surgical or dietary interventions or which aim to have a physiological effect
- reported outcomes for a study population of adults (since mostly children are treated within NOK and PSY rehabilitation centres)
- had samples of fewer than 10 participants in both treatment and control group
- were single case presentations/series/reports, this includes experimental studies that used multiple baseline, post-test or pre-test/post-test designs with fewer than 10 participants
- were non-systematic reviews
- were editorials or expert opinions
- did not use standardised and/or validated outcome measures and/or outcome measures reported by the parents or tutors
- are non-published work
- were published in other languages than English, Dutch or French
- did not clearly describe methods (for example brief reports) and results or had significant discrepancies
- were published before 1997

Some extra criteria were generated for the following databases:

- ERIC: only peer-reviewed articles
- PsycINFO: only journal articles

In this report, for each study is described to which criteria (Cochrane or Gersten) it complied and the global appraisal of the article based on these criteria. No clearly defined cut-off was used, as the difference between a small shortcoming and a severe shortcoming on a quality item in a study is difficult to make when only 0-0.5- or 1 can be administered. Therefore studies with a quite high score on Cochrane or Gersten could still be excluded because a severe shortcoming interfered with the results. To avoid complete subjectivity, the quality of all included studies was mentioned in the reviews itself and in the summary of findings tables. The score obtained on Cochrane or Gersten should be treated as an indication and should be handled with care. In addition, all the individual criteria that studies eventually met were summarized in tables. These tables are not included in this report, but they are available for consultation. Based on this appraisal, again some studies were disqualified. For every research question, a 'search results table' (see Appendix to Chapter 3) is made adding up all results from the different databases. The approved studies, for each research question, are summarized in the 'Summary of findings table' (see Appendix to Chapter 3).

As this report tries to answer questions concerning evidence based treatment methods for abovementioned disorders, some explanations are at place concerning the use of the term 'evidence'. The GRADE system is used (see Appendix to Chapter 3)[10]. An extra remark can be made concerning the frequently used terms 'efficacy' and 'effectiveness'. Seemingly similar in meaning, they express distinctly different concepts. Whether or not an intervention can work under ideal conditions is related to 'efficacy'. A treatment can be mentioned as 'efficacious' when it proves to be superior to (usually) placebo or another treatment.

On the other hand, 'effectiveness' is the question whether an intervention works in routine care. A more pragmatic approach is used within these studies. In this review, the original terms were reproduced. The majority of the included studies investigate the 'efficacy' of a particular intervention.

3.2 ATTENTION DEFICIT HYPERACTIVITY DISORDERS

3.2.1 Introduction

As described in the methodology, if an existing systematic review of good quality dealing with the main research question of this study could be found, it was taken as the basis for the literature review of this part of the study and further updated as necessary. The flow of the search strategy and reading process of articles dealing with evidence-based treatment methods for attention deficit hyperactivity disorders (ADHD) is put in Appendix to Chapter 3.

The following review about the evidence-based treatments for ADHD is to a large extent based on the review of Pelham and Fabiano (for critical appraisal of this review, see Appendix to Chapter 3) [11].This review is an update to the Pelham, Wheeler and Chronis (1998) review of the psychosocial (i.e. non-drug based) treatment literature on ADHD [12]. Their conclusions in 1998 revealed that for children with ADHD and other externalizing disorders, across different reviews and evaluation methods, there has been consensus that behavioural parent training and behavioural classroom management are evidence-based psychosocial treatments for ADHD [11]. On the other hand, the literature available at that time did not support individual cognitive therapy (typically aiming to improve self-control of the child over his or her inattention and impulsive behaviour in other settings…) as an effective, evidence-based therapy for ADHD. The 1998 review is not discussed because the studies used for this review are published before 1998 and those are not situated in the scope of our research (see earlier).

An update was desirable because a review of the studies investigating the effectiveness of behaviour therapy for ADHD can amplify and clarify initial conclusions.

Moreover, stimulant medication is also approved as an evidence based treatment for ADHD and there is currently considerable controversy with regard to whether behaviour modification has relevance in the different treatments. By way of illustration, prominent researchers have stated that behavioural interventions are insufficiently effective for treating ADHD as compared to medication [13]; (S. P. Hinshaw, 2007; S. P. Hinshaw, Klein, R.G., & Abikoff, H. , 2002; P. S. Jensen, 1999; MTACG, 1999b). These conclusions are difficult to reconcile with the literature cited above [12]. Stimulant medication, considered as the other and more commonly employed evidence based treatment for ADHD has a strong evidence base [14].

Stimulant medication produces acute short-term improvements in on-task behaviour, compliance with teacher requests, classroom disruptiveness and parent and teacher ratings of ADHD symptoms. Further, we must consider that medication use has increased the last years. Pelham and Fabiano indicate that many reviews have concluded that medication is more effective than behaviour modification [15-17]. Remarkably, these reviews have all based their conclusions on the small number of large, between-group studies in the literature—most prominently the MTA. [18] state that service referrals are also far more likely to be made for medication rather than behavioural treatment for ADHD.

In conclusion, medication remains much more widely used in the medical profession and considerable controversy remains regarding the role of behaviour modification in treatment planning. "It is therefore critical to provide an update to the earlier review to determine whether the evidence base for behavioural interventions has improved sufficiently for them to be viewed as viable alternatives to medication, as first line treatments and/or as important adjunctive interventions" [11], pp. 6).

Pelham and Fabiano indicate that perhaps the most well-known and widely cited study of treatments for ADHD is the MTA-study of ADHD ([19];[20-23]. The MTA-study is an archetype for the entire treatment literature on ADHD.

Like all studies, the MTA answers some important questions, but it does not resolve all of them and creates others [24, 25].

3.2.2 Methodology: details for the ADHD literature search

For this study, we found references to a total of 488 potentially appropriate studies searching the different databases. Of these, 99 studies were not found. A total of 63/488 studies were excluded based on screening of the full text, so 326 studies remain to discuss.

As abovementioned, the review of Pelham and Fabiano (2008) forms the basis of our review. The review of Pelham and Fabiano (2008) meets the Cochrane criteria (see Appendix to Chapter 3) and includes studies published between January 1997 and September 2006 and intend to update and assimilate the recent literature on psychosocial evidence-based treatments for ADHD, yielding conclusions regarding the current state of the science for behaviour modification for ADHD and guidance regarding future directions for the study of effective interventions for this disorder [11].

The Pelham review (2008) included 46 studies, 41 of those were also found through searching the different databases. Seventeen of the 41 studies were single-subject designs and were already excluded based on the screening of the title, abstract or full text because generalisation of single-subject studies remains problematic -especially when studying disorders or pathological situations instead of healthy volunteers- and because this report aims to advise the government based on well-established conclusions about topics concerning groups of patients and general working methods in rehabilitation centres rather than few individual cases [11].

The other 24 studies that were selected based on screening of the full text and also included in the Pelham review (2008) were consulted to find more detailed information, so the Pelham review (2008) is used as a guideline. It concerns the following studies [26,27; 24,28,29,30,31,32,33,34; 29,35; 21, 36-46]. Two of these studies ([33] and [34]) were in the Pelham review 'in press', but meanwhile were published.

Since the Pelham literature search includes studies up to September 2006, all studies published before 2007 were excluded and the literature from that point on, (for search strategy and evidence tables, see Appendix to Chapter 3) will be discussed.

More detailed: a total of 56 studies were published in 2007, of these 34 studies were excluded based on screening of the full text. So 22 studies of 2007 were left to discuss: 8 studies of 2007 were not found, 2 of 2007 studies were excluded based on the quality criteria, 5 studies of 2007 were overlapping with the review of Pelham and Fabiano (2008) and 7 studies of 2007 were discussed.

Finally, it should be noted that the review of Pelham and Fabiano (2008) only included studies in which behavioural treatment alone was compared to other treatment options [11]. Thus, studies of multimodal treatment compared to medication but not to behavioural treatment alone (e.g.,[47] were not included.

Because of this reason, the studies of Abikoff and colleagues (2004) and Hechtman and colleagues (2004) [48] that focus on psychosocial treatment as a component of multimodal treatment, has been discarded from the Pelham review [13]. However, these studies do belong to the scope of our study and therefore are included.

Consistent with older reviews and meta-analyses, behavioural interventions for ADHD in the form of behavioural parent training, behavioural classroom management and intensive, summer program-based peer interventions are supported as evidence-based treatments for ADHD. No treatment outcome studies that supported the use of nonbehavioural psychotherapeutic or cognitive-behavioural treatments (i.e., individual therapy, play therapy, cognitive therapy) for ADHD were identified [11];[15].

The current review discusses successively the description and the evidence of these three categories of behavioural intervention behavioural parent training, behavioural classroom management and behavioural peer interventions, based on the review of Pelham and Fabiano (2008) [11].

Because most studies contributed to a combination of criteria for behavioural parent training, contingency management in classroom settings or contingency management in peer/recreational settings, they are discussed once and not separately in each chapter.

As already mentioned, two older studies [13]and [48] are additionally described which also consider the question under research but are not included in the Pelham review. These studies include alternative psychosocial treatment (social support and problem-solving communication training).

More detailed information about the evidence is listed in the summary of findings table (see Table 1). This table contains information regarding subject characteristics, sample size, type/duration of intervention, therapeutic speciality(ies), purpose of intervention, used method of effect evaluation, reported effects (effect sizes) and study quality.

Pelham used the Nathan and Gorman criteria (2002) for classifying the study designs in his review. These quality criteria [49] were adopted in the current review. The reported effects of these studies included in the Pelham review are classified in three columns: effect size of behavioural intervention versus no treatment, effect size of behavioural intervention versus alternative treatment and effect size of behavioural intervention change score. In the Pelham review effect size is used as a mean of describing the magnitude of specific treatment effects in the studies reviewed for the three types of behavioural intervention. Analogously, the studies of 2007 and multimodal studies are considered in the summary of findings tables.

3.2.3 Evidence-based interventions for ADHD

3.2.3.1 Behavioural interventions

In general

Description of behavioural interventions

Behavioural therapy relies on accurate training of and constant application by both parents and teachers of the child to improve the behaviour of the child. It consists of four main principles: positive reinforcement, time-out, response cost and token economy [50]. Positive reinforcement entails rewards or privileges for the child that behaves well or academically performs well. A time-out removes access to rewards or privileges. In response cost, prior earnings of rewards and privileges of the child are withdrawn with each undesirable action. A token economy combines positive reinforcement and response cost to reward or punish the behaviour or academic performance of a child.

It is important to differentiate behaviour therapy from psychological interventions, directed to the child and designed to change the child's emotional status (for example play therapy) or thought patterns (for example cognitive therapy or cognitive-behaviour therapy) [51].

Behavioural intervention versus No Treatment Control

In this column, positive effect sizes mean improvement attributed to behavioural intervention relative to a control condition. In all studies, behavioural interventions yielded improved functioning. It is important to consider that effect sizes varied as a function of the type of the study design. For example: for in between-group design studies effect sizes ranged from -0.03 to 1.07 (median = 0.47) and effect sizes for in within-subject design studies ranged from 0.10 to 2.39 (median = 0.64).

Behavioural intervention versus Medication

Compared to medication, effect sizes in between-group design studies ranged from -0.24 to 0.20 (median = 0.11). This indicates a little advantage compared to medication. In within-subject studies, effect sizes ranged from -3.39 to 0.47 (median = -0.27), meaning larger effects for medications.

Behavioural intervention Change Score

In the between-group design studies, effect sizes ranged from -0.16 to 1.63 (median = 0.61). These substantial effect sizes show a positive effect of behavioural interventions compared to pre-treatment functioning. This pattern was consistent across studies of behavioural parent training, behavioural classroom management and behavioural peer interventions.

Behavioural Parent Training

Description of the intervention

Symptoms of ADHD not only affect the daily functioning of a child but also may influence the functioning of the parent-child relationship [52]). Behavioural parent training consists of sessions in which parents are educated about ADHD and are introduced to a range of behavioural strategies for increasing attention and behavioural organization and reducing defiant and difficult behaviour [43]. Parenting skills such as structuring the environment, setting rules, giving instructions, anticipating misbehaviours, communicating, reinforcing positive behaviour, ignoring, employing punishment and implementing token systems were dealt with. Other important elements are psychoeducation and cognitive restructuring of parental cognitions (van den Hoofdakker, van der Veen-Mulders, Sytema, Emmelkamp, Minderaa et al., 2007). The behavioural parent trainings were typically group based and consisted of 8 to 16 sessions (with a higher mean in the MTA-study, which had a longer duration than other studies); different manuals, but with the same overall content, describing the behavioural parent training were used.

Evidence of the intervention

In the Pelham review 22 studies of behavioural parent training for ADHD are included [11] (see also Appendix to Chapter 3): [24]; [27];[28];[53];[54]; Danforth, Harvey, Ulaszek, & McKee, 2006; [31];[33];[35];[21, 36, 37, 39, 43-46, 55-58]. Four studies are single-subject designs and not discussed in this review [54, 57] [53]. The study of Owens and colleagues (2005) was not found searching the databases and therefore not discussed in this review.

In the study of Sonuga-Barke and colleagues (2001) children with preschool ADHD were randomly assigned to either parent training, parent counselling and support (attention placebo), or a waiting-list control group. Parent training in this study consists of behavioural strategies given to parents to modify the behaviour of their children and to re-establish positive relationships within the family.

In parent counselling and support, parents have the possibility to reflect on the parenting process in a supportive and non threatening setting. Sonuga-Barke and colleagues (2001) demonstrated the evidence of the clinical value of parent training in the treatment of preschool ADHD compared with waiting-list control group and parent counselling and support. They stated that the comparative effectiveness of parent training over parent counselling and support suggests that training in specific behavioural strategies is a key element of effective psychosocial intervention. Parent training was associated with large decreases in preschool children's AD/HD symptoms. They showed the effectiveness of a parent training when delivered as a part of specialist tier-two services for preschool AD/HD children [43] . A more recent study of Sonuga-Barke and colleagues (2004) used a randomized controlled design (parent training or waiting list control) to assess the potential benefits of translating this parent training package form specials tier-two, to routine tier-one settings with non-specialist nurses [44]. The intervention package was identical to that used in the previous trial of Sonuga-Barke and colleagues (2001). Sonuga-Barke and colleagues (2004) concluded that the previously observed effective benefits to preschool AD/HD children and their parent of parent training delivered in specialized settings (Sonuga-Barke et al., 2001), are not generalized when delivered as part of routine primary care by non-specialist nurses [44].

In the MTA-study [59] 579 children were assigned randomly to medication management (with strict follow-up), behavioural treatment, combined treatment or community care-as-usual, over the course of 14 months.

The behavioural treatment in this study included parent training, child focused treatment (more specific a summer treatment program) and a school-based intervention organized and integrated with the school year. Medication management consists of titration of methylphenidate hydrochloride followed by monthly visits. Combined treatment included a combination of the two last mentioned treatments and the community care group received treatment from community providers.

All four groups of management strategies showed marked reductions in symptoms over time, with significant differences among them in degrees of change. The results showed that combined treatment and medication management treatments were clinically and statistically superior to behavioural treatment and community care in reducing children's ADHD symptoms [59]. The behavioural treatment group was not significantly different from the community comparison group, despite the fact that 67.4% of community-treated subjects received ADHD medications during the treatment period. Moreover more than three fourths of the subjects given behavioural treatment were successfully maintained without medication throughout the study. From this large study it can be concluded that psychosocial treatment is effective in treating children with ADHD, albeit less effective than combined treatment and medication management treatments. The medication management treatment (more intensive follow-up and higher dose of methylphenidate than medication given in usual community care) appears to be superior in reducing core-ADHD-symptoms; whereas the combined treatment (medication + psychosocial treatment) yields better results than medication alone or psychosocial treatment alone in non-ADHD-fields of functioning, (like improving aggressive behaviour or internalizing symptoms, improving child-parent relationship etc.) Also, it should be noted that the average dose of medication was lower in the combined group as compared to the medication management group.

Further analyses of subgroups of this large sample were separately reported [21]. In this report however, for children with *comorbid OOD/CD disorders* no consistent difference in outcome could be found for any of the four treatment regimes. In the same subanalysis, it was found that for patients with *comorbid anxiety disorder,* behavioural treatment only yielded results as good as medication management or combined treatment. Another finding concerned *the low-income group*, in which the effect of combined treatment was superior, especially regarding social interactions.

The global results of the MTA-study are confirmed by Wells, Pelham, Kotkin, Hoza, Abikoff and colleagues (2000) who studied more in detail the psychosocial treatment modalities in the MTA-study [23].

The key finding in the study of Wells, Chi, Hinshaw, Epstein, Pfiffner and colleagues (2006) is that a multimodal treatment strategy yielded optimal effects on an objectively coded measure of positive and constructive parenting [60].

The studies of Sonuga-Barke and colleagues (2001) [43] and the MTACG [21, 59] stated that behavioural parent treatment is a well-established treatment for ADHD if the behavioural treatment conditions in each case were equivalent to or better than an alternative treatment. The studies also need to have an adequate statistical power, a good study design, a manual and need to be conducted by independent teams of investigators. The study of [28] –in which families were randomly allocated to enhanced behavioural family intervention, standard behavioural family intervention or a waitlist control group- supports the use of behavioural family intervention in the treatment of preschool children with co-occurring disruptive behaviour and attentional/hyperactive difficulties, notably directly addressing parenting practices.

In the study of Tutty and colleagues (2003), children with an ADHD diagnosis were treated with stimulant medication and their parents were randomly assigned to an intervention group (behavioural and social skill program for children with ADHD and their parents) or a control group. Based on parent ratings, they demonstrated that the intervention group showed significant improvements in ADHD functioning in the home setting versus the control group [45]. Tynan and colleagues (1999) also reported similar results about the combination of social skills training and behavioural parent training [11, 58].

The following 3 studies all use a pre-post-design, which is a considerably weaker study design as compared to RCT's.

McCleary and Ridly (1999) report an evaluation of a clinic based, parent skills training and education group for parents of adolescents with ADHD. In this study, the parent education group includes a manual based program which provides information about ADHD and training in problem solving and parenting skills.

In a pre-post design, they proved the effectiveness of a group parent education approach to help parents of adolescents with ADHD. Their findings support including parent education as part of the multimodal treatment of ADHD [39].

The study of Weinberg (1999) also used a pre-post design to examine the effect of a parent training program for ADHD youngsters with particular emphasis on potential changes in the parents. The program consists mainly of teaching about ADHD and behaviour management techniques. The results indicate an increase in parental knowledge and understanding of ADHD and behaviour management skills and a modest decrease in parental stress in managing their children with ADHD. However behavioural improvement of the children with ADHD was not found at the completion of the program, all the children were treated with medication during the program. This can be discussed in the context of a possible ceiling effect from medication [46].

The study of Danforth and colleagues (2006) evaluates, in a pre-post design, the effects of group parent training on parent behaviour as well as the hyperactive and the aggressive/defiant behaviour of their children. They used parameters established in the Behaviour Management Flow Chart. In this study, parent training included didactics on the features and etiology of ADHD and its relationship to defiant/aggressive behaviour, as well as parenting skills that adhered to parameters established in the behaviour management flow card. The results show that training for parents reduced hyperactive, defiant and aggressive behaviour of children with ADHD, improved parenting behaviour and reduced parent stress (Danforth, Harvey, Ulaszek, & McKee, 2006).

The following study by Kapalka (2005) is an RCT focusing on teacher management. Nevertheless, Pelham considers this study as a contribution to the criteria for behavioural parent training.

Kapalka (2005) investigated the effectiveness of reducing repetition of commands in obtaining compliance. To examine this, 86 teachers of children with ADHD were randomly assigned to treatment or control groups. Children in the treatment group exhibited a significant reduction in non-compliance, while children in the control group did not. They used Barkley's technique, in which teachers issue a command, repeat it one time if necessary and if no compliance was obtained, proceed to warn the child (one time only) of a consequence and then administer that consequence. This technique proved to be effective and should be recommended to teachers of ADHD children [37].

Notably, one study [24] failed to provide evidence for the behavioural parent training as a well-established treatment for ADHD [11]. Barkley and colleagues (2000) [24] found that a behavioural parent training program offered through the school to families of high-risk children for ADHD is ineffective at reaching and assisting these families with children's behavioural problems. Probably this ineffectiveness is due to a large drop-out and inconsistently attending the program.

With the addition of some studies [12, 21, 28, 43], behavioural parent training interventions clearly meet task force criteria for a well-established treatment for ADHD and for substantial evidence of efficacy in the Nathan and Gorman system [11].

Although the multimodal treatment study (MTA) of ADHD included behavioural classroom management and behavioural peer interventions, the abovementioned measures reflected home behaviour and parenting skills. So it is plausible to assume that the behavioural parent training was the active ingredient in producing these changes. However, because all three components were present, a contribution of behavioural classroom management or behavioural peer interventions to these improvements is described [11].

In summary -except the early mentioned study of Barkley and colleagues (2000) [24]- for behavioural parent training interventions compared to a waitlist, the effect sizes for group-design studies ranged form 0.47 [36] to 0.70 [28]. When behavioural parent training interventions are compared to alternative psychosocial treatments (such as nondirective parent counselling and support) a clear benefit of behavioural parent training is reported. The study of Sonuga-Barke and colleagues (2001) reports an effect size of 0.66 [43].

Psychosocial treatment delivered as parental behaviour training is effective in ADHD children, when compared to no treatment. However it is less effective than medication treatment alone, when applied on short term.

This parental behavioural treatment is typically group based and consists of 8 to 16 sessions (or more in studies of longer duration); manuals describing the parental behavioural training are used.

Behavioural Classroom Management

Description of the intervention

School-based interventions could help children with ADHD to behave appropriately in school and to perform better academically ([61]). Behavioural classroom interventions involve regular consultation with the child's teacher regarding the use of behaviour modification strategies. Classroom interventions focus primarily on disruptive and task engagement ([52]). Consultation usually starts with psychoeducation about ADHD and identification of specific target behaviours. Then, teachers are instructed regarding the use of specific behavioural techniques, including verbal praise, planned ignoring, effective commands and time out, as well as the daily report card and/or more extensive individualized or classroom-wide contingency management programs such as a point or token economy system [53] .

Evidence of the intervention

Pelham and colleagues (1998) found that behaviour based classroom interventions are an empirically supported treatment for children with ADHD [12]. In the current Pelham review; 23 new studies investigating behavioural classroom management for ADHD, were identified [11]. They replicated that behavioural classroom management is a well-established treatment for ADHD ([62], [24]; [53],[63]; [31]; [32](Study 1); [32](Study 2); [33],[64],[65] [34]; [21, 38, 40, 41, 55, 56, 66-70]. Nine mentioned studies are single-subject designs and are not included in this review ([62]; [53]; Coles et al., 2005;[64]; [66-70]

In the study of Barkley and colleagues (2000) [24] 'disruptive' children were randomly assigned to four treatment conditions: no treatment control, parent training only, fullday treatment classroom only and the combination of parent training with the classroom treatment. The multiple behavioural interventions provided through a specialized kindergarten classroom were: an intensive token system; response cost, over-correction and time-out from reinforcement; group cognitive-behavioural self-control training; group social skills training; group anger control training; a daily school report card with home-based reinforcement and/or behaviour modification programs. They demonstrated that the special classroom intervention program resulted in the reduction of hyperactive, impulsive, inattentive and aggressive behaviour as well as improvement of social skills, self-control and home adaptive functioning. Pelham and colleagues (under review a) also used contingency management procedures, but in a summer program classroom setting.

In the MTA-study [59] the school-based treatment was a part of the behavioural treatment and consisted of teacher consultation focusing on classroom behaviour management strategies and behaviourally trained paraprofessional aide working directly with the child.

The abovementioned three studies, measures included ADHD symptoms rated by teachers, teacher-rated social skills and independent observations of classroom behaviour. All measures revealed significant improvement relative to control conditions [11].

Additionally, five large well-designed crossover studies using a within-subject design (average N=35) with similar dependent measures and similar results supported this conclusion (e.g., [29],[65], [34], [38, 41].

Evans and colleagues (2005)[32] reported preliminary data on the Challenging Horizons Program, a school- based program for middle school youth with ADHD. The study used a quasi-experimental design including a treatment group and a community care group.

The participants in the treatment condition attended an after school program which included elements of behavioural parent training, behavioural classroom management and behavioural peer interventions. They suggested that the Challenging Horizons Program effectively improved the social and academic functioning of many students. Another study of Evans and colleagues (2007) [33]. employed a teacher consultation model showing small effects that accumulated over the middle school years. Their findings revealed cumulative long-term benefits for the treatment group as measured by parent ratings of ADHD symptoms and social functioning [33].

Dopfner and colleagues (2004) evaluated the effectiveness of behavioural therapy and pharmacological treatment within an adaptive and individually tailored multimodal treatment for children with ADHD. Children with ADHD were assigned to either behavioural therapy (including continued psychoeducation) or medical management with methylphenidate and psychoeduction. Their results suggested that 26% of the children with ADHD, who started with behaviour therapy after initial psychoeducation, received a combined treatment in later treatment stages. In 82% of the children who were treated with medication first, required additional behaviour modification in later treatment stage. They concluded that both, behavioural therapy and combined treatment are effective interventions within an adaptive and individually tailored multimodal treatment strategy [31].

Altogether, the evidence of behavioural classroom management for ADHD is substantial [11]. As considered above, many of these behavioural classroom management interventions also included behavioural parent training. But even though dependent measures were taken in classroom settings, behavioural parent training often was included as part of the behavioural classroom management (e.g., the MTA study). Thus, in many of these studies, components of behavioural parent training may have contributed to the effects of the behavioural classroom management.

Summarized, it can be stated that for behavioural classroom management, compared to no treatment, the effect sizes of between group-design studies ranged from -0.03 [24] to 0.44 ([40]. The effect sizes for within-subjects design studies were considerably larger. A comparison of behavioural parent training, behavioural classroom management and alternative treatment (medication) is provided in the MTA study [59]. The MTA study showed that behavioural interventions were equivalent to community treatment (mostly medication) and the medication management in the MTA was modestly better than behavioural intervention (effect size = -0.24). Kolko and colleagues (1999), on the contrary, found a modest advantage (effect size = 0.3) for behaviour classroom management versus medication [38].

Behavioural Peer Interventions

Description of the intervention

Most children with ADHD experience difficulties in developing and sustaining peer relationships. Peers are often critical about the behaviour of children with ADHD. They consider their behaviours to be impolite or offensive [52]. Peer interventions include instructions in social skills, social problem-solving and behavioural competencies. These interventions attempt to enhance social competence by encouraging close friendships and decreasing undesirable and antisocial behaviours. Social skills training intends to promote prosocial behaviours that include cooperation, communication, participation and validation [52].

Evidence of the intervention

Twenty-one of the studies in the Pelham and Fabiano review (2008) included interventions and measures that focused on peer interactions and/or relationships:[26;29; 53]; Coles et al., 2005; {Evans, 2005 #9}(Study 1); [32](Study 2);[33;65;64;35; 11, 38, 41, 42, 70-75]. Nine studies are single-subject designs and therefore not discussed in this review [64;53, 63, 64, 70-75].

Several of these studies are traditionally, weekly, group-based, clinic-based and/or social skills training groups. They focus on discussion and role play of key social skills and are provided autonomously or with concurrent behavioural parent training and/or with medication.

Pelham and Fabiano (2008) concluded that traditional, office-based social skills trainings produce minimal effects and the social validity of these interventions is questionable [11].

Frankel and colleagues (1997) [35] included in their study only children with an ADHD diagnosis for whom medication was prescribed. They were assigned to a waitlist group or a treatment group. The intervention consisted of concurrent child and parent sessions of social skills treatment. They concluded that children with ADHD gained most by a combination of social skills training, collateral training for their parents (aiding in transfer of their child's social skills treatment) and stimulant medication.

The participants in the study of Antshel and Remer (2003) [26] were children with ADHD taking medication. They were randomly assigned to social skills training or a no-intervention control condition. In contrast with the abovementioned studies, this study involved a child social skills group without a concurrent parenting group. Their results failed to demonstrate the efficacy of social skills training groups for children with ADHD.

Although Pfiffner & McBurnett (1997) reported a beneficial effect of concurrent behavioural parent training and child social skills groups on parent reports of social behaviours, no studies replicated their results [76].

In the abovementioned studies, participants were medicated with stimulants. Concurrent medication can hamper the detection of other intervention effects so in these studies it complicates measurement of effects.

Next to this, other treatment studies used a different approach to target peer relationships and functioning in recreational settings. The majority of these studies were conducted in summer treatment programs. The current Pelham review (2008) describes several studies reporting the effect of behavioural interventions for peer problems in recreational settings, typically summer treatment programs. The review contains two between-group studies [56], five cross-over studies [29;65; 38, 41, 56] and well-controlled single-subject studies. The latter are not further discussed because they are not situated in the scope of this research. Additionally, in all of these studies the summer treatment program was a component of the MTA. The summer treatment program is a comprehensive, manualized behavioural treatment program [29]. The interventions are typically day-long programs conducted for multiple weeks (5 to 8), delivering 200-400 hours of treatment, versus 10-20 hours (for multiple weeks) in a typical weekly social skills training program. The program consists usually of classroom sessions, coached group play in recreational activities, a systematic reward/response cost program (point system, time out) implemented by paraprofessional staff, sports skills training, social skills training, problem-solving skills training, home rewards from parents for daily report cards goals (individualized target behaviours from classrooms and recreational activities) involving peer interactions and parent training. Additionally to traditional social skills, these programs focused on teaching sports skills and team membership skills (Pelham & Fabiano, 2008).

Different from the studies that have assessed traditional social skills training, these summer treatment program studies involve objective observations and frequency counts of social behaviours in addition to adult ratings of social skills as outcome measures [11].

In the study of Pelham and colleagues (2000), all participants were randomly assigned to the behaviour-only treatment (children were unmedicated) or combined treatment (children were medicated). As part of the behavioural treatment of the MTA, children participated in a summer treatment program.

Those authors found that adjunctive stimulant medication produced relatively few incremental gains of acute functioning and had no effect on rate of improvement for children receiving the summer treatment program and parent training [42].

The results of the study of Chronis and colleagues (2004) (Chronis et al., 2004) supported the efficacy of the summer treatment program as an intervention for ADHD across multiple domains of impairment, including classroom and peer functioning.

Another study ([65]) supported the use of time-out procedures as an intervention for children with ADHD in classroom and recreational settings. Time-outs seem an important component of behavioural treatment packages.

In their study, Kolko and colleagues (1999) evaluated the separate and incremental effects of 2 doses of methylphenidate and behavioural modification in children with ADHD and comorbid disruptive disorders. Because methylphenidate and behaviour modification had certain unique main and incremental effects, they concluded that this extends findings supporting the combination of methylphenidate and behaviour modification and suggests that integrated studies evaluate multiple dimensions of functioning in novel setting [38].

The study of Pelham and colleagues (2005), which took place in the context of the summer treatment program, expands upon previous studies documenting the effect of the summer treatment program and behavioural interventions for ADHD. They also observed that low doses of medication yielded enhanced effects in combination with behavioural treatment [41].

Most studies indicated that intensive behavioural interventions (like the summer-camp treatment) are effective and often produced acute effects comparable to those produced by medication [11]. .

In the study of Pelham and colleagues (2005), the odds ratios for the probability that children reached their daily goals on placebo behaviour modification days versus placebo no behaviour modification (no treatment) days, were measured. They showed that children were nearly 19 times more likely to succeed on days when behavioural modification was applied. Children were 4-13 times more likely to reach their daily individual treatment goals when medication (versus placebo) was added to behavioural modification and they were 6-10 times more likely to reach their daily goals when behavioural modification (versus no behavioural modification) was added to medication. So the odds ratios demonstrated the exceptional strong benefits that individuals gain from combined versus unimodal treatment in a summer camp environment [41].

Pelham and Fabiano (2008) pointed out that the incremental benefits of behavioural parent treatment in summer programs cannot be ruled out and that this treatment may be quite important for generalization. As with behaviour classroom management, behavioural parent training is typically provided concurrently in intensive summer programs and home-based contingencies are often employed ass well.

Pelham and Fabiano (2008) pointed out that similar to the abovementioned studies, the dependent variables were objective and measured in the peer-based recreational settings, rather than in the home setting. The studies of Pelham and colleagues (under review b, 2000) yielded beneficial results of intensive summer program treatment.

The number of studies about this treatment indicates that behavioural interventions, implemented in peer group/recreational settings (summer treatment programs), meet criteria for a well-established treatment according to the Task Force criteria[dd].

dd Task Force criteria Task Force on Promotion and Dissemination of Psychological Procedures, 1995; http://www.cochrane.org/).

However, it is important to pay attention to some difficulties with behavioural peer intervention. Behavioural peer intervention is more costly than behavioural parent training and behavioural classroom management, more difficult to implement in community settings and the least available of the evidence based treatments for ADHD[11].

In summary, the effect sizes of behavioural peer interventions compared to a waitlist or no treatment group ranged from 0.29 [26] to 0.40 – 0.63 (Pelham et al., 2008a). Like behavioural classroom interventions, the reported effects of behavioural peer interventions are generally of a larger magnitude in within-subject design studies.

Cross-over design studies provide considerable evidence supporting peer interventions over medication. The included studies in the Pelham review indicated a benefit of behavioural peer intervention over medication in recreational settings. Only in one study (Kolko et al., 1999), medication was superior to behavioural peer intervention in an unstructured enrichment setting (effect size = -3.39) [38].

Alternative psychosocial treatment

Social support

Description of the intervention

As discussed above, in the study of Sonuga-Barke and colleagues (2001) children with preschool ADHD were randomly assigned to either parent training, parent counselling and support (attention placebo), or a waiting-list control group. Parent counselling and support gives parents the opportunity to reflect on the parenting process in a supportive and non threatening setting [43].

Evidence of the intervention

In summary, although a supportive context and a willing listener are valuable elements of parenting support, they are not sufficient to produce behavioural change in a child who has ADHD [43] . It could be demonstrated that the attention control group was clearly inferior to the behavioural parenting group and thus not meeting criteria for an evidence-based treatment.

Problem-solving communication training

Description of the intervention

The problem-solving communication training program contains three major components for changing parent-adolescent conflicts: problem solving, communication training and cognitive structuring [27]. Problem-solving includes training parents and teens in a five-step problem-solving approach. Communication training involves helping parents and teens to develop more effective communication skills while discussing family conflicts. Cognitive restructuring implies helping families detect, confront and restructure irrational, extreme or rigid belief systems, held by parents or teens about their own or the other's conduct. These skills were practiced using direct instruction, modelling, behavioural rehearsal, role playing, feedback and homework assignments [27].

Evidence of the intervention

In the study of Barkley and colleagues (2001) [27], ADHD teens and their parents were assigned to 18 sessions of problem-solving communication training alone or behavioural management training for 9 sessions followed by 9 sessions of problem-solving communication training. A previous study of Barkley and colleagues (1992) compared these two forms of treatment separately and found both equally effective at the group level of analysis. Although problem-solving communication did not differ from behavioural parent training in either study, it is unclear whether Barkley and colleagues (1992) had sufficient statistical power to conclude that the treatments were equivalent, because the sample sizes were relatively small [77]. Therefore problem-solving communication training was not classified according to the task force criteria [11]. Another remark is proposed by Smith and colleagues (2000): they have highlighted the small literature on ADHD treatment in adolescents [78]. Problem-solving communication treatment seems promising for this group and needs more research along with other interventions. In summary no conclusions can be drawn concerning the effectiveness of problem-solving communication training. More in depth research is needed.

3.2.3.2 Additions from studies of 2007

The review of Benner-Davis and Heaton (2007) included studies –published between 1990 and 2007- largely overlapping with the studies of the Pelham review [50]. They concluded that treatment with stimulant medication was the most efficacious intervention. Children with ADHD, who took stimulant medications, showed the greatest improvement in behaviour when compared to other interventions such as behavioural therapy or family counselling. However, a combination of both stimulant medication and behaviour therapy revealed synergistic efficacy.

De Boo and Prins (2007) reviewed social skills training outcome studies, published between 1995 and 2005, for children with ADHD [79]. Of the six selected intervention studies, more than half were also included in the Pelham review. In four of these studies positive effects about the efficacy of social skills training intervention on social competence in children with ADHD were found.

The studies included in the 'Practice parameter for the assessment and treatment of ADHD3 were published in the period from 1996 to 2006. Almost all studies were also included in the Pelham review.

In addition to this, the study of Van den Hoofdakker and colleagues (2007) investigated the effectiveness of behavioural parent training in clinical practices as an adjunct to ongoing routine clinical care from a child and adolescent psychiatrist, including family support and pharmacotherapy for the child when appropriate. The authors stated that this study is the first randomized controlled trial in children with ADHD that allowed patient selection in a naturalistic way. Children with ADHD were randomly assigned to 5 months of behavioural parent training with concurrent routine clinical care or to 5 months of routine clinical care alone (care as usual, including supportive counselling, psychoeducation, pharmacotherapy and eventually crisis management). Their conclusion was that adjunctive behavioural parent training enhances the effectiveness of routine treatment of children with ADHD, particularly in decreasing behavioural and internalizing problems, but not in reducing ADHD symptoms or parenting stress [80].

The randomized controlled trial of Pfiffner and colleagues (2007), evaluated the efficacy of a behavioural psychosocial treatment for children with ADHD predominantly inattentive type (ADHD-IA) integrated across home and school. The children were randomly assigned to the Child Life and Attention Skills Program or a no-treatment control group. The treatment combined three modalities namely teacher consultation, parent training and social skills training. They concluded that behavioural psychosocial treatment (specifically adapted for ADHD-IA and coordinated among parents, teachers and children) was efficacious in reducing symptoms and impairment associated with ADHD-IA [81].

The multi-centre, randomized open-label study of Prasad and colleagues (2007) aims to give insight into the impaired functioning of children with ADHD and to assess the effectiveness of atomoxetine in comparison with standard current therapies for ADHD. A total of 201 patients were randomized assigned to atomoxetine or standard current therapy. In this study, standard current therapy was defined as any intervention regarded by the investigator/treating physician that would benefit the patient and that they would use as appropriate in their standard clinical practice (including the option of no therapy). Standard current therapy could include any combination of medicines (apart from atomoxetine) and/or simple behavioural counselling approaches of childeren but no formal course of structured psychotherapy. The results of this study showed that atomoxetine is superior to standard current therapy in addressing broader efficacy and functional outcomes in UK children/adolescents with ADHD [82].

Shalev and colleagues (2007) investigated the efficacy of a pioneering intervention program grounded in a contemporary theoretical framework of attention and designed to directly improve the various attentional functions of children with ADHD. Children with ADHD (N=36) were randomly assigned to an experimental group or to a control group.

In the experimental group, children received the computerized progressive attentional training program (composing of four sets of structured tasks that uniquely activate sustained attention, selective attention, orienting of attention and executive functioning). Respectively, the Computerized Continunuous Performance Task, the Conjunctive Search Task, the Combined Orienting and Flanker Task and the Shift Stroop-like Task are designed to improve the abovementioned functions. The children in the experimental group showed a significant improvement in nontrained measures of reading comprehension and passage copying as well as a significant reduction of parents' reports of inattentiveness. The control group did not show significant improvement. They concluded that the academic and attentional improvements were primarily due to the computerized progressive attentional training.

Nevertheless, there are some limitations. The study did not include any objective attentional measure assessing attentional difficulties before and after training in the evaluation battery. Further, it is not possible to determine whether the improvement observed is time limited or whether it represents an enduring change in underlying ability without any long-term follow-up. Finally, there is no evaluation of teachers regarding the children's classroom functioning and academic performance [83].

In the study of van der Oord and colleagues (2007), children were randomized to treatment withmethylphenidate or treatment with methylphenidate combined with multimodal behavioural therapy to investigate the additional value of a short-term, clinically based, intensive multimodal behaviour therapy to optimally titrated methylphenidate in children with ADHD. The multimodal behavioural therapy consisted of a child and parent behavioural therapy and a teacher behavioural training. The authors found no evidence for the additive effect of multimodal behavioural therapy next to optimally titrated methylphenidate. So this study does not support that optimally dosed stimulant treated children with ADHD should routinely receive a multimodal behavioural treatment to reduce ADHD and related symptoms [84].

3.2.3.3 Multimodal treatment

The 3-year follow-up MTA-study of Jensen and colleagues (2007) examined 36-month outcomes, 2 years after the treatment by the earlier discussed MTA-study [59]. The earlier discussed MTA-study described results after more than 1 year of prospective and carefully monitored treatment in a randomized clinical trial of children who were assigned to one of four different intervention groups. An initial follow-up evaluation was 10 months following the completion of treatment. The report of Jensen and colleagues (2007) attempted to clear our understanding of long-term ADHD outcomes and their relationship to medication persistence. They found that by 36 months, the earlier advantage of receiving 14 months of the medication algorithm was no longer apparent. This is possibly due to age-related decline in ADHD symptoms, changes in medication management intensity, starting or stopping medications altogether or other factors not yet evaluated [85]. This study was the companion paper of the study of Swanson and colleagues (2007) [86]. The finding of Jensen and colleagues, that current medication use at the 36-month assessment was associated with a slight disadvantage rather than a relative advantage led to two hypotheses. The self-selection bias contributed to lack of medication advantage at the 36-month assessment of the MTA-study of children with ADHD and the overall improvement over time obscured treatment effects in subgroups with different outcome trajectories. The self-selection hypothesis was not confirmed, but the authors found suggestive evidence of residual but not current benefits of assigned medication in the second subgroup and small current benefits of actual treatment with medication in the first subgroup.

Abikoff and colleagues (2004) conducted a two years lasting study in which they looked at a possible additional effect of psychosocial treatment to medication alone for 103 ADHD children without a diagnosis of CD (conduct disorder) and/or learning disorder, who responded to short-term methylphenidate at the beginning of the treatment [13]. However, about 50% of the children showed ODD (opposite-deviant disorder) at the beginning of the study. Abikoff and colleagues used a randomized controlled design to compare medication (methylphenidate) alone to the combination of medication with multimodal psychosocial treatment that included parent training and counselling, social skills training, psychotherapy and academic assistance or with attention psychosocial

control treatment. All three treatment arms had produced significant improvement on child-, parent-, teacher- and psychiatrist ratings/observations. No differences were found between all ratings/observations. Even in the subgroup presenting ODD (opposite-deviant disorder) at the beginning of the study, no additional effect of the combined treatment could be found after two years. The authors concluded that there is no clear advantage in adding long-term psychosocial treatment to medication to improve ADHD and oppositional defiant disorder (ODD) symptoms. This result confirms the outcome found in the MTA-study.

Hechtman and colleagues (2004) used the same design as Abikoff and colleagues (2004) to test the hypothesis that intensive multimodal psychosocial intervention (that includes academic assistance and psychotherapy) combined with methylphenidate significantly enhances the academic performance and emotional status of children with ADHD compared with methylphenidate alone and with methylphenidate combined with non-specific psychosocial treatment (attention control)[13].

The authors concluded that in young children with ADHD without learning and conduct disorders, there is no support for academic assistance and psychotherapy to enhance academic performance or emotional adjustment. But significant improvement occurred across all treatments and was maintained over two years [48].

In summary, the combination of multimodal treatment and pharmacological therapy did increase the effectiveness of treatment.

3.2.4 Conclusion

There are differences of opinion regarding the effectiveness of behavioural interventions for ADHD and their role in the treatment of ADHD [11].. In the Pelham review there are several studies that support behavioural treatments -such as behavioural parent training, behavioural classroom management and behavioural peer interventions- as well established treatments for ADHD. Effect sizes of the impact of behavioural interventions range from small to large, depending on the type of intervention, setting and control condition. They often approach and sometimes match or exceed the effects of active stimulant medication, particularly in domains of functional importance to children with ADHD.

The reported results demonstrate that behavioural interventions have sufficiently significant effects in comparison with no treatment. It can be justifiably offered as a first line intervention. According to the Task Force criteria, behavioural interventions are recognized treatments for children with ADHD.

However, except the study of Shalev and colleagues (2007), there is found no evidence for office-based psychotherapies conducted solely with the child or cognitive or other child-directed therapies [83]. "Behavioural interventions are the only evidence-based psychosocial interventions for ADHD" [11], pp. 50). Behavioural parent training should be implemented initially and behavioural classroom management should be concurrently implemented with behavioural parent training. More intensive studies are needed to examine the effects of intensive behavioural peer interventions. The literature suggests that clinic-based weekly social skills groups are not effective.

Two alternatives for increasing treatment intensity should be initiated when abovementioned behavioural interventions have been insufficient, namely adjunctive or increased dose of stimulant medication or enhanced and more complex behavioural interventions and/or more restrictive education placement.

In short term, the medication management treatment (including intensive medication follow-up) appears to be superior in reducing core-ADHD-symptoms, whereas the combined treatment (medication + psychosocial treatment) probably yields better results than medication alone in treating additional behavioural problems, attaining preset goals, improving child-parent relationship etc. The latter finding could raise the assumption that combined treatment is superior in children with comorbid ODD or CD, but this could not be confirmed. However, in subgroups with comorbid anxiety, behaviour therapy alone (delivered intensively as in the MTA-study) yields results comparable to medication only.

Alternatively, it can also be suggested that pharmacotherapy could be the first line intervention in ADHD, with behavioural treatments utilized only after multiple drugs and combinations of drugs have been tried.

Indeed, the 14-month intensive medication algorithm of the MTA-study yielded significant advantage for the first 24 months. It should be noted however that the MTA-study found no clinically or statistically significant treatment differences by 36 months. Intensive medication management may only make a persistent long-term difference if it is maintained with the same intensity.

Because there was no untreated control group in the MTA-study and because all of the treatment groups showed improvements in terms of relevant symptomatology at 36 months of age, it is possible that all of the treatments (medication, medication+ psychosocial and psychosocial alone) worked, but at different rates or during different time periods. An important clinical message to be taken from the MTA findings is that all of the treatment groups showed significant improvement over time.These data suggest that negative outcomes from previous studies should not be presented and be discussed in isolation (Jensen et al., 2007).

No evidence was found for nonbehavioural psychotherapeutic or cognitive-behavioural treatments (i.e., individual therapy, play therapy, cognitive therapy) for ADHD were identified between 1998 and February 2008.

In conclusion, most children with ADHD and their families require follow-up throughout childhood (and probably adulthood), to support and promote engagement and adherence to the selected regimen for protracted periods of time. A brief, time-limited treatment regimen –whether it be behavioural, pharmacological, or combined- that is not followed-up will not be a sufficient and effective intervention for children with ADHD.

Other well-known treatment methods like biofeedback, psychoeducation and working memory training were not the scope of this literature review. Therefore no conclusions could be drawn about the efficacy/effectiveness of these interventions. However, since the search strategy for this review was set broad, with search terms like "therapy", "education", "rehabilitation", "intervention", etc. (see Appendix to chapter 3), these subjects would probably have been picked up as well in the search results.

By searching the different databases, no articles were found concerning the effects and differences between mono- and multidisciplinary treatment. In the included studies, treatment interventions were done by a researcher. Therefore, no conclusions could be formulated about the evidence of the kind and the number of disciplines needed to be incorporated to deliver evidence-based psychosocial treatments. It is also remarkable that no statements could be made about the effectiveness of treatment in comorbid disorders. The included studies only investigated psychosocial treatments within children with the only diagnosis 'ADHD'. The co-existence of other comorbid disorders was not mentioned in the description of the subjects in the included studies. This is noticeable because comorbid disorders are widespread. More research is needed concerning these topics. The mean age of the participants in the included studies is about 8 years; therefore conclusions about the effectiveness of these psychosocial treatments could only be generalized for this age group.

3.2.5 Discussion

In order to translate findings from evidence-based literature to practical advice for professionals working with children with ADHD, clinical guidelines are developed. These guidelines provide recommendations for effective practice in the management of clinical conditions and are based upon thorough evidence-based research. The findings from this review were compared with recent clinical guidelines in the National Guideline Clearinghouse[ee] and the Tripdatabase[ff].

ee http://www.guideline.gov
ff www.tripdatabase.com

In order to assess the quality of the clinical guidelines, an appraisal document was developed by the 'Appraisal of guidelines research and evaluation' (AGREE)[gg] (see Appendix to Chapter 3) and the score is provided in Table 34.

Table 34: Appraisal of clinical guidelines (AGREE)

	AGREE score	Reliability
ADHD, Diagnosis and management of ADHD in children, young adults and adults (NICE, 2008)	70 to 80	High
European guidelines for hyperkinetic disorder [87]	40 to 50	Low
ADHD in children and Youg people (SIGN, 2005)	70 to 80	High
Practice parameters for the assessment and treatment of children and adolescents with ADHD [88]	60 to 70	Good
ADHD, University of Michigan Health (ICSI, 2007)	60 to 70	Good
Evidence based clinical practice guideline for outpatient evaluation and management of attention deficit/hyperactivity disorder (Cincinnati Children's Hospital Medical Center , 2004)	60 to 70	Good

In general, no real inconsistencies were found between the findings from the review and the clinical guidelines from the National Institute for Health and Clinical Excellence (NICE, 2008)hh, the guidelines provided by Taylor and colleagues (2004) [87], evidence based clinical practice guidelines from the Cincinnati Children's Hospital Medical Center (2004), guidelines from the Scottish Intercollegiate Guidelines Network (SIGN, 2005)[ii], guidelines from Pliszka S. and the AACAP work group on quality issues (2007)[jj 88], guidelines from the Institute for Clinical Systems Improvement (ICSI, 2007)[kk].

The main recommendations within these clinical guidelines for diagnosis and management of children with ADHD are slightly different for pre-school children and school-age children. For preschool children the recommendation is made not to use pharmacological therapy as first-line care. Most guidelines support behavioural individual/group based parent training, and emphasize that this should be used as first-line approach. For school-age children, behavioural individual/group based parent training remains the most important recommendation, but group or individual cognitive behavioural therapy (although supported by less evidence) or social skills training can also be considered. For parent training, NICE considers 8-12 sessions as an optimal duration, but this is not supported by clear evidence. Behavioural classroom management and behavioural peer interventions are also recommended as evidence-based treatments for children with ADHD. Only when severe ADHD is diagnosed in school-age children, pharmacological therapy should be offered as first line care but together with parent training and the involvement of teachers (NICE, 2008). Guidelines from the Scottish Intercollegiate Guidelines Network (SIGN, 2005) follow the multimodal treatment for children with ADHD but they recommend pharmacological therapy as first line care for the treatment of core characteristics of ADHD.

gg http://www.agreecollaboration.org, www.wokresearch.com, www.cbo.nl

hh NICE is an independent organisation responsible for providing national guidance on the promotion of good health and the prevention and treatment of ill health. NICE produces guidance in public health (promotion of good health and prevention of ill health), in health technologies (the use of new and existing medicines, treatments and procedures) and clinical practice (the appropriate treatment and care of people with specific diseases and conditions). http://www.nice.org.uk/

ii ' Attention deficit and hyperkinetic disorders in children and young people', http://www.sign.ac.uk/

jj ' Practice parameters for the assessment and treatment of children and adolescents with attention-deficit: hyperactivity disorder'.

kk ' Diagnosis and management of attention deficit hyperactivity disorder in primary care for school-age children and adolescents', http://www.icsi.org/

They state that a combination of medication with nonpharmacological therapies is recommended because the dosage of medication can be lower to achieve the same results as when only a high dose of medication is provided.

Guidelines from Taylor and colleagues (2004) only add the use of summer camps with social skills training (also found in the review) [87]. Guidelines formulated by Pliszka and colleagues (2007) [88], clinical practice guidelines from the Cincinnati Children's Hospital Medical Center (2004) and guidelines from the Institute for Clinical Systems Improvement (ICSI, 2007) do not add relevant/evidence-based new elements to these abovementioned recommendations.

3.3 PERVASIVE DEVELOPMENTAL DISORDERS

3.3.1 Introduction

Given the heterogeneity of pervasive developmental disorders (or autism spectrum disorders) and the knowledge that there is no single known aetiology, a range of therapies and interventions have been developed. In this review, the interventions for pervasive developmental disorders were divided into six different categories: three categories following the classic triad of impairments, namely: 'interventions for social interactions', 'interventions for language and communication' and 'interventions for restricted, stereotyped, repetitive repertoire of interests and activities' and further three general approaches, namely 'general behavioural interventions', 'general early and comprehensive interventions' and 'specific and other interventions'.

Generally, a total of 394 potentially appropriate studies were found searching the different databases as described in the methodology (see earlier). Of these, 42 studies could not be retrieved. A total of 265 studies were excluded based on screening of the full text. Some of these studies are not describing their methodology very well in the abstract, for example, they do not mention if they incorporated a control group, they do not mention the number of included participants in their abstracts… or they seem very promising after reading the abstract, while the full text is disappointing. These are the main reasons why so much articles are excluded based on a screening of the full texts. From the remaining 87 studies, 36 studies were excluded due to overlap with other articles or reviews and 22 studies were excluded based on the defined quality criteria. In Appendix to Chapter 3, an overview of the search strategy for articles dealing with evidence-based treatment methods for pervasive developmental disorders is provided in a 'Flow'.

3.3.2 Evidence-based interventions for pervasive developmental disorders

3.3.2.1 Interventions for social interactions

Introduction

A profound deficit in social reciprocity skills is the core underlying feature of autism spectrum disorders. Children with autism spectrum disorders suffer from direct and indirect consequences related to social interaction deficits. The social impairments in individuals with autism spectrum disorders are diverse and involve speech, linguistic conventions and interpersonal interactions (White, Keonig, & Scahill, 2007). In this part, we focus on interventions specially created to improve the social interactions for children with autism spectrum disorders, namely social skills training, imitation sessions, joint attention training, specific multimedia and Lego© therapy.

Other interventions like social stories, video modelling, virtual reality technology, training in theory of mind or false belief, peer mediated interventions, self management and self monitoring are also perceived under this category. However, no articles of good quality criteria (as described in the methodology) were found for these interventions. This also means that they could not be perceived as 'evidence based treatment methods'. Interventions based on the principles of applied behaviour analysis have also been shown to improve social interactions, but these kinds of interventions are reviewed further.

For this part of the review, 13 articles were found. From these articles, 7 articles were approved and therefore included in this part of the review [89]; [90],[91-95]), 1 article was excluded based on overlap [96] and 5 articles were excluded due to not fulfilling the quality criteria [97-101]. More detailed information about the evidence is listed in the summary of findings table for interventions for social interactions (see Appendix to Chapter 3).

This table contains information regarding subject characteristics, sample size, type/duration of intervention, therapeutic speciality(ies), purpose of intervention, used method of effect evaluation, reported effects (effect sizes) and study quality.

Social Skills training

Description of the intervention

Kroeger and colleagues (2007) assigned 25 children to a direct teaching group (using video-modelling to teach play and social skills) or a play activities group (using unstructured play to teach play and social skills). These two treatment groups were differentiated in only two areas: (1) the direct teaching group participated in a video modelling curriculum (watching the videos and the subsequent play/activity stations), and (2) the direct teaching group received primary reinforcement during the course of the video modelling. All other activities were the same for both groups including: beginning and ending circle times, visual schedules during each session to transition activities, 2:1 student to facilitator ratio, secondary reinforcement for prosocial behaviours, behaviour management for inappropriate behaviours and introduction of identical toys and materials commensurate with the video modelling curriculum [94].

Evidence of the intervention

From the pre- and post-measured time, both groups improved in their prosocial behaviours. Both the direct teaching group and the play activities groups improved in their learning readiness and group orienting behaviours over the course. The direct teaching group made more gains in social skills than the play activities group, but the direct teaching group did not show more improvement over time than the play activities group .

The review of White and colleagues (2007) was excluded based on overlap. They included 14 different studies, from which we could exclude 4 articles because they were published before 1997, 7 studies could be excluded because they were single subject designs with pre-post test meting, 2 studies were doctoral dissertations and 1 study was also retrieved by our search strategy [102]. This last study did not fulfil our quality criteria; it consists of two groups of 9 children and was therefore excluded.

Imitation sessions

Description of the intervention

In the following studies of Escalona and colleagues (2002)[89], [92] and [90], the imitation sessions are based on Nadel and colleagues (2000) version of the classic still-face procedure (phase 1-3) with some modifications (phase 4) [103]. The procedure consisted of four distinct phases: (1) still-face 1, the child enters an unfamiliar room alone where an adult is sitting still like a statue with no facial expressions or movements; (2) intervention phase: each child receives either an imitative interaction or a contingent reaction. In the imitative interaction group, the experimenter imitated everything the child did.

In the contingent interaction group, the experimenter responded immediately to every behaviour and sound exhibited by the child, but without using an imitative behaviour; (3) still-face 2, which is the same as still-face 1 and (4) free play: a spontaneous play episode between the experimenter and the child. This kind of intervention has a very short duration; it takes 3 minutes for each phase.

Evidence of the intervention

Three comparable studies of Escalona and colleagues (2002)[89], Field and colleagues (2001) [90] and Heimann and colleagues (2006)[92] used Nadel's version of the still phase procedure in order to compare two different intervention strategies, namely (a) an imitative interaction and (b) a contingent but non-imitative interaction. All abovementioned authors **randomly assigned** samples of 20 children with autism spectrum disorders to each of the intervention strategies. In the study of Field and colleagues (2001) [90], the still phase procedures were administered during three repeated sessions, in the study of Heimann and colleagues (2006)[92] the still phase procedures were administered twice, while study of Escalona and colleagues (2002) only presented the still phase procedure once. However, the results were partly similar. Escalona and colleagues (2002) reported that, during the second still face episode (phase 3), the children in the imitation condition spent less time in gross motor activity and more time being close to the stranger as well as touching her, than did those in the contingent-only condition [89]. Similarly, Field and colleagues (2001)[90] reported that, during their third session (in the final free play episode), the children in the imitation condition increased their proximal social behaviour toward the stranger (e.g. physical closeness and touching), while children in the contingent-only condition did not. The analysis of Heimann and colleagues (2006) also revealed a significant increase of both proximal and distal social behaviour for the imitation group, which confirms the two other studies. In addition to this, an increase in elicited imitation was also observed for children in the imitation group, but not in the contingent group [92].

Joint attention training

Description of the intervention

In the joint attention intervention, applied by Kasari and colleagues (2006) and Gulsrud and colleagues (2007), children were taught to engage in joint attention acts such as pointing and showing and were also encouraged to share attention between people and objects through the use of eye contact. They compared this intervention to a symbolic play intervention, which aims to teach children to engage with toys in a developmentally appropriate sequence through the use of functional and pretend play acts. The first half of both interventions consisted of direct teaching at the table top of either developmentally appropriate joint attention or symbolic play skills and the second half consisted of generalizing these skills during free play interactions [91, 93].

Evidence of the intervention

Kasari and colleagues (2006) **randomly assigned** 58 children with autism to three groups: a joint attention intervention group, a symbolic play intervention group and a control group. Results indicated that both intervention groups improved significantly on certain behaviours, in comparison with the control group. Both the joint attention group and the symbolic play group showed significant greater improvement in initiating shows and significantly more gains in coordinated joint looks, in comparison with the control group, but there was no significant difference between the play and joint attention group. The play group showed significantly more types of symbolic play over time compared to the joint attention intervention group and the control group. Children generalized their gains in interactions and responses to the interactions with their mother [93]. In 2007, Gulsrud and colleagues extended this previous study by reporting on additional generalization findings of the joint attention and symbolic play intervention by examining on affect, gaze, joint attention behaviours and verbalizations In this study they **randomly assigned** 35 children to a joint attention intervention group and a symbolic play intervention group. Three novel probes, consisted of auditory and visual stimuli, were administered to determine if joint attention skills were mastered.

The results of this study revealed that children in the joint attention intervention group were more likely to acknowledge the probe and engage in shared interactions between the intervener and probe upon termination of intervention. The joint attention intervention group improved in the proportion of time spent sharing coordinated joint looks between intervener and probe.

The generalisation of joint attention skills to a novel probe did occur for the joint attention intervention group and provides some effectiveness for this kind of intervention [91].

Specific multimedia: 'Emotion Trainer'

Description of the intervention

Silver and Oakes (2001) designed the computer program 'Emotion Trainer' to help people with autism spectrum disorders to recognize and predict emotions in others. It is one component in learning to understand emotions and apply this information in the right context. The Emotion Trainers consists of 5 sections: the fist section is made to allow the user to become familiar with how key emotions look as a facial expression, the second part deals with the fact that situations and events could trigger an emotional response,

the third is developed to teach the principle that getting what you want rather make you happy and not getting what you want is rather make you sad, the fourth principle is designed to teach that mental states can provoke an emotional response and the last session deals with the absence or presence of disliked and liked events or objects and the implications on people's feelings [95].

Evidence of the intervention

Silver and Oakes (2001) **randomly assigned** 22 children with autism or Asperger syndrome to two groups: one group had their normal lessons and used a computer program to teach them to better recognize and predict emotional responses in others; the other group had only their normal lessons. Results showed that the experimental group improved significantly more than the control group on the number of errors made on the 'Strange Stories score' and on the 'Emotion Recognition Cartoons'. The authors only observed a time effect on the 'Facial Expression Photographs', meaning that both groups improved their scores over time and the effect of the intervention was not significantly greater. The number of times the child used the computer program significantly correlated with their improvement in score on the 'Strange Stories' and on the 'Emotion Recognition Cartoons', but not with improvement on the 'Facial Expression Photographs' [95].

Lego© therapy

LEGO© building materials have been adapted as a therapeutic modality for increasing the motivation to participate in social skills interventions and providing a medium through which children with social and communication handicaps can interact. The article of LeGoff and Sherman (2006) [97] did not meet the quality criteria, due to not describing the applied intervention. Therefore, this article was excluded.

Conclusion

A few studies were found concerning interventions specially created to improve the social interactions for children with autism spectrum disorders. Three articles were found for imitation sessions, showing a significant increase of this intervention on both proximal and distal social behaviour in children with autism spectrum disorders. Through this, these studies provide some evidence regarding imitation sessions for children with autism spectrum disorders, but more in depth research including follow-up is certainly necessary. Joint attention training could also be a promising intervention. There is also some evidence regarding this intervention, but more research is also needed. For social skills training, specific multimedia and Lego© therapy, no (sufficient) evidence has been found to support the effectiveness of these interventions for children with autism spectrum disorders.

3.3.2.2 *Interventions for language and communication*

Introduction

The definition of autism spectrum disorders indicates a developmental disability significantly affecting social interaction and verbal and nonverbal communication. Charlop-Christy and Carpenter (2002) [104] formulated several approaches to teach communication skills to children with autism spectrum disorders. Some of these approaches include sign language, electronic devices and symbol systems. All of these mentioned techniques can be used in conjunction with spoken language and with each other. The approach that this part of the review will focus on is the symbol systems, specifically the Picture Exchange Communication System. For other approaches like computer mediated communication interventions, voice output communication and facilitated communication, no studies of good quality as defined in the methodology were found.

Five articles were found, from which 3 articles were approved on quality criteria [105]; [106, 107] and 2 articles were excluded based on not fulfilling these quality criteria [108] and [107]. More detailed information about the evidence is listed in the summary of findings table for interventions for language and communication (see Appendix to Chapter 3).

Picture Exchange communication system

Description of the intervention

The Picture Exchange Communication System, developed by Bondy and Frost in 1994 [109], intends to teach communication skills by using pictures and symbols on cards with the hopeful outcome of meeting functional needs of the child and increased spoken initiation ([110]. It relies on behavioural principles, particularly reinforcement techniques (Howlin et al., 2007). PECS consists of six phases, each with its own specific goal, going from Phase I -teaching the child to initiate a request for a desired item through the exchange of a picture for that item, at close proximity to a communicative partner- to Phase VI -teaching the child to comment spontaneously and in response to a question- [111] . Children with autism spectrum disorders tend to be visual-spatial learners and the PECS allows communication with that emphasis because information exchange is made possible by pictures on cards. Other benefits of PECS are that it requires few prerequisite skills; it can be taught quickly; it requires little complex motor movements and it is low-cost and portable. The aspect that truly makes the PECS unique to other communication systems is that it requires initiation from the child to convey their preference [112].

Evidence of the intervention

The following recent studies from Yoder and Stone (2006) [107], [111] and Howlin and colleagues (2007) investigated the effects of PECS [106]. The first study of Yoder and Stone (2006) compared the effects of PECS with 'Responsive Education and Prelinguistic Milieu Teaching', whereas the other two studies compared PECS to a non-intervention control group [107].

Yoder and Stone (2006) conducted a **randomized group experiment**, comparing the effects of 2 communication interventions, namely 'Responsive Education and Prelinguistic Milieu teaching' (RPMT) and 'PECS' on spoken communication in 36 preschoolers with autism spectrum disorders. RPMT is composed of two components: one for parents (responsive education) and one for children (Prelinguistic Milieu Teaching (PMT)). Responsive education for parents intends to support parents in playing with and talking to their children in ways that are thought to facilitate children's communication and language development. PMT is a play-based incidental teaching method designed to teach gestural, nonword vocal, gaze use and later word use as forms of clear intentional communication for turn-taking, requesting and commenting pragmatic functions. Their findings revealed that PECS was more successful than RPMT in increasing the amount of nonimitative spoken communication acts and the amount of different nonimitative words used at the post treatment period.

When the researchers did not consider the initial characteristics of the children, no main effect for treatment was found 6 months after the treatment ended.

However, when they considered children's initial object exploration, maintained treatment effects were detected. The growth rate of the amount of different nonimitative words was faster in the PECS intervention group than in the RPMT intervention group for children who began treatment with relatively high object exploration. In contrast, analogous slopes were steeper in the RPMT intervention group than in the PECS intervention group for children who began treatment with relatively low object exploration [107].

The **quasi-experimental study** of [111] investigated the impact of mastery of PECS Phase I until Phase III on the communication of children with autism spectrum disorders. The final phase in this study, namely Phase III, intends to teach the child to exchange the correct picture for an object by teaching them picture-to-object discriminations and their corresponding object-to-picture relations. In this study, the authors formed two groups: a PECS intervention group consisting of 24 children and a non-intervention control group consisting of 17 children. They observed 3 times the PECS group (6 weeks before the intervention, 1 week before the intervention and 1 week after the intervention took place) and 2 times the control group (1 week before the PECS group had intervention and 1 week after). They identified a considerable increase in communicative initiations by children who had received 15 hours of PECS teaching at Phases I, II and III.

Additionally, significant improvements in other measures of communicative interaction were evident for the PECS group, namely an increase in the child-initiated communications which received a response from an adult; a decrease in the number of communicative initiations by an adult, which provided no opportunity for the child to respond and an increase in the communicative initiations by an adult, which received a response from the child. These improvements were not present in the previous non-intervention period among the PECS group or in the comparable non-intervention period in the control group. In the control group, they identified a significant increase in the number of communicative initiations by an adult, which provided an opportunity for the child to respond. However, the increase in the number of adult initiations was not accompanied by an increase in the responses from the child [111] . In this study, the children made significant improvements but they did not generalise this to other areas, which is an important shortcoming of the PECS intervention.

Howlin and colleagues (2007) **randomly assigned** 84 children to 3 groups: an immediate treatment, a delayed treatment and a no treatment group. These results indicate modest effectiveness of a PECS teacher training/consultancy. Rates of pupils' initiations and use of symbols in the classroom increased, although there was no evidence of improvement on other areas of communication. Treatment effects were not maintained once active intervention ceased. Despite earlier claims that PECS can enhance children's use of speech, this study failed to demonstrate any increase in spoken language or scores on language tests and the children continued to show significant impairments and abnormalities in communication. This may be caused by the fact that the sample in this study showed considerable impairment in terms of limited communication abilities and a low developmental quotient, as well as being older than in some other studies [106].

Conclusion

It is clear that there is a definite need for appropriate interventions for children who have an autism spectrum disorder, are visual (-spatial) learners and/or are nonverbal. Individualized interventions in the area of communication are necessary to enhance their communication abilities [112]. The evidence-base for PECS includes two RCT's ([106, 107] and one quasi-experimental study [111] , with all studies showing some benefits. PECS can provide one effective element of a wider 'eclectic' treatment method, although the failure of treatment effects to maintain suggests that another ongoing intervention is likely to be required. Randomised control trials of other language and communication programmes have shown almost no effect of intervention for children with severe communication disorders [113].

Thus, the present findings, albeit limited, are particularly important for informing educational practice for severely impaired, non-speaking children with autism spectrum disorders [106]

3.3.2.3 *Interventions for restricted, stereotyped, repetitive repertoire of interests and activities*

Introduction

'Music therapy' and 'auditory integration training were distinguished here. These therapies teach the child with autism spectrum disorders other and acceptable behaviour instead of repetitive, stereotyped behaviour. Therefore, these kinds of interventions were placed under the category 'interventions for restricted, stereotyped, repetitive repertoire of interests and activities'. For other approaches like sensory integration therapy, visual therapy (with prism or coloured optical overlays), movement therapy, sensorimotor manipulation techniques (Doman, Delcato, Bobath, craniosacral and Sherborn therapy) and creative and expressive therapy, no studies of good quality as defined in the methodology were found, and consequently no evidence. Medication is also an important intervention for restricted, stereotyped, repetitive repertoire of interests and activities but it does not deal with the scope of this review. For this part of the review, 14 articles were found, two of which (both reviews) were included [114] and [115], 11 articles were excluded based on overlap ([116]; [117], [118],[119-126] and 1 article was excluded based on quality criteria [127]. More detailed information about the evidence is listed in the summary of findings table for interventions for restricted, stereotyped, repetitive repertoire of interests and activities (see Appendix to Chapter 3).

Music therapy – musical interaction therapy

Description of the intervention

'Interactive therapy' using music has been used for many years in an attempt to improve the child's co-ordination and communication skills. Musical interaction is sometimes described as a type of non-verbal or pre-verbal language allowing children to communicate on a more emotional, relationship-orientated level. The terms 'music therapy' and 'musical interaction therapy' are used to cover a wide range of interventions. These interventions can involve a therapist with a music therapy qualification, or may involve speech therapists of people with other types of qualification' [116]. [128] described music therapy as 'a systematic process of intervention wherein the therapist helps the client to promote health, using musical experiences and the relationships that develop through them as dynamic forces of change'.

Evidence of the intervention

A Cochrane review, published in 2006, was found concerning 'music therapy for autistic spectrum disorder'. Because of the high quality of Cochrane reviews, 2 other articles [37, 125]and 4 reviews [116];[122-124] about this intervention method are not described. They were already implemented in this Cochrane review or they did not pass Cochrane.quality criteria

In the Cochrane review, selection criteria were randomised controlled trials or controlled trials comparing music therapy added to standard care to 'placebo' therapy, no treatment or standard care. Three small studies [129];[130];[131]) were included in this review, all with the comparison 'music therapy' versus 'placebo therapy'. Outcomes were assessed for non verbal and verbal communicative skills and behavioural problems. They reported a medium effect size (2 RCT's, N = 20, SMD 0.50 CI 0.22 to 0.79) on non-verbal (gestural) communicative skills, which is seen as a clinically relevant magnitude when comparing an active therapy condition to a placebo therapy. The effects on verbal communicative skills were smaller (2 RCT's, N = 20, SMD 0.36 CI 0.15 to 0.57), ranging between a small and a medium effect size. But this can still be seen as a clinically relevant magnitude because the 'placebo therapy' possibly contained not only 'non-active' but also some of the 'active ingredients' of music therapy. Data on behavioural problems were limited and the effect size was small (1 RCT, N = 4, SMD -0.24 CI -0.45 to -0.03).

The authors concluded that the included studies were of limited applicability to clinical practice. The methodological strength of evidence was weakened by the limited information on randomisation methods and allocation concealment, the limited use of assessor's blindness, the lack of using standardised scales and the small sample size. There were also factors contributing positively to the strength of evidence, namely no performance bias (co-intervention) or attrition bias (drop-out) and a high inter-rater reliability. These findings indicate that music therapy may help children with autism spectrum disorder to improve their communicative skills and to reduce behaviour problems but more research is needed to examine whether the effects of music therapy are enduring and to investigate the effects of music therapy in typical clinical practice ([114]).

Auditory integration training

Description of the intervention

Treatments to overcome variations in auditory sensitivity commonly encountered in people with autism have been developed and are collectively called 'auditory integration therapies'. They include auditory integration training (AIT) or Berard's method, the Tomatis method and Samonas sound therapy. These kinds of therapies have been developed to improve abnormal sound sensitivity and autistic behaviours in individuals with autism spectrum disorders. Abnormal responses to sensory stimuli may be the manifestation of auditory hypo- or hypersensitivity. These abnormal responses are not a core criterion for diagnosis of autism spectrum disorder but nevertheless, they are an important and common characteristic encountered in autistic individuals [120].

Evidence of the intervention

A Cochrane review (2004), written by Sinha, Wheeler and Williams was found [115]. This review included the same studies as the other review of [120, 121] and the studies of [126]and Best and Milne (1997) [118]. These abovementioned articles were therefore excluded based on overlap. The review of Dawson and Watling (2000) did not meet the Cochrane quality for systematic reviews and was therefore excluded [127].

The Cochrane review of Sinha and colleagues included 6 studies [132];[133]; [126, 134-136]. Selection criteria were RCTs of adults or children with autism spectrum disorders in which auditory integration therapy (AIT) or other sound therapies, involving listening to music modified by filtering and modulation, were applied. A total of 171 individuals aged 3 to 39 years were comprised. Seventeen different outcome measures were used and only two outcomes were used by three of more studies. Therefore meta-analysis was not possible due to very high heterogeneity or presentation of data in usable forms. The authors summarized that three studies [132]; [126, 134]did not demonstrate benefit of AIT over control conditions and three trials [135, 136] and [133] reported improvements at three months for the AIT group based on improvements of total mean scores for the Aberrant Behaviour Checklist (ABC), which is of questionable validity. Finally, [135] reported improvements at three months in the AIT group for ABC subgroup scores. No significant adverse effects of AIT were reported. The authors concluded that more research is needed to inform parents' carers' and practitioners' decision making about this therapy for individuals with autism spectrum disorders [115] .

Conclusion

'Music therapy' and 'auditory integration training' were studied in depth. Insufficient evidence was found to support the effectiveness of these interventions. More adequate research is needed.

3.3.2.4 General behavioural interventions

Introduction

Problem behaviours are common in children with autism spectrum disorders and they can become major barriers to effective education and social development. Behavioural interventions are often used to promote social and adaptive behaviour in children with autism spectrum disorders [137]. Behavioural therapy is the application of basic psychological principles of learning to human behaviour.

The purpose is to change behaviour, this by experimental analysis of the behaviour and by understanding the principles by which behaviour is determined (for example environmental events) [138]. Applied behaviour analysis is based on the scientific principles of behaviour and is targeted at ameliorating the core deficits in autism spectrum disorders.

It starts with focusing on teaching small measurable units of behaviour using discrete trial treatment (DTT) in mass trials. The treatment is based on systematic, step-by-step teaching using prompts and reinforcements. The intervention is provided for 30-40 hours a week in a one-on-one setting by experienced behavioural therapists. Children with autism spectrum disorders are taught skills like attention, basic discrimination, language and communication, daily living, socialization, play, fine and gross motor control and pre-academics [139].

'Behavioural and skill-based early interventions', 'parent training and pivotal response training (PRT)', 'Developmental, Individual Difference, Relationship model', 'teacher training in applied behaviour analysis' and 'cognitive behaviour therapy (CBT) were distinguished here. For this part of the review, 44 articles were found. From these articles, 14 articles were approved and therefore included in this part of the review [140]; [141], [142] [137],[143],[139], [144-151], 23 articles were excluded based on overlap [152],[153],[154],[155],[156],[157], [78], [138], [146], [158-170] and 6 articles were excluded based on quality criteria ([171]; [172]; [173-176].

In this part of the review some parts are overlapping with the following part namely 'general early and comprehensive interventions' because the distinction is not always very clear. This part of the review deals with behavioural interventions, whereas the other part deals with interventions generated for very young children and eclectic interventions.

Most of the following studies are a comparison of behaviour interventions with other kind of treatments. More detailed information about the evidence is listed in the summary of findings table for general behavioural interventions (see Appendix to Chapter 3).

Behavioural and skill-based early interventions

Evidence of the intervention

A HTA report, published in 2001, was found concerning the evidence for the effectiveness of behavioural and skill-based early intervention in young children with autism spectrum disorders [137].

Doughty systematically reviewed the literature. He identified five secondary studies which met their selection criteria [152]; [154],[157],[138], [177]. Bassett and colleagues (2000) concluded that the claim of Lovaas (1987), stating that half the children with pervasive developmental disorders achieved normal or near-normal development and placement in schools, is unconfirmed by independent research [152]. This review did not support that the children will achieve normal functioning due to Lovaas treatment. They conclude that due to methodological weaknesses, the findings of Lovaas (1987) [178] can not be validated as conclusive. The Cochrane review of Diggle and colleagues (2002) [154] included the studies of [160], [78] and [161], [162] . They presented some evidence in favour of the effectiveness of early intervention, but this had to be considered with great caution due to the small number of included studies. Finch and Raffaele (2003) indicated some positive effects on IQ, class placement and adaptive behaviour for most children receiving intensive behavioural intervention (IBI), but they state that it is difficult to extent this conclusion for all children with pervasive developmental disorders [157]. There are limitations associated with the studies searching for evidence. [177] incorporated different systematic reviews (ECRI, 1999; BCOHTA 2000 and [167] in their review concerning IBI: Lovaas therapy, Rutgers method, Denver method and TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children). TEACCH is a widely used system in Belgium. It emphasizes two principles: (1) structuring the environment to promote skill acquisition and (2) facilitating independence at all levels of functioning [139]. The study from Tsang, Shek, Lam, Tang and Cheung (2007) [179], investigating the effects of TEACCH, was excluded because it is a brief report (see Appendix to Chapter 1 - exclusion criteria).

They conclude that most of these intensive interventions were shown to be effective in producing developmental gains, increases in IQ and less restrictive school placement, but evidence remains limited due to methodological limitations and weaknesses of included research. It still has to be determined if any one programme is more effective than another. Finally, McGahan (2001) also reviewed the literature systematically [138]. Five conducted assessments or reviews were included (ANAES, ECRI, BCOHTA, [167], AHFMR), like Ludwig and Harstall, McGahan summarizes that there are many methodological limitations and weaknesses in research.

All five secondary studies drew attention to the lack of well-conducted research on early intervention for pervasive developmental disorders in young children. These five reviews summarized that there is insufficient evidence to conclude about best practice. The relationship between the amount (per day and total duration) of any form of early comprehensive treatment programme and the overall outcome need to be researched more in depth in the future [152].

Doughty (2004) [137] also included five primary studies [153];[180];[155];[165, 181] that fulfilled the defined quality criteria. Bibby and colleagues (2002) found in their multi-cohort study that parent-managed intensive behavioural interventions did not reproduce results from clinic-based professionally directed programmes, like Lovaas therapy [153]. Doughty also comprised two randomised controlled trials, namely from Smith and colleagues (2000) and [180]. Smith and colleagues (2000) compared an intensive treatment group with a parent training group. The former group had better measures of intelligence, visual-spatial skills, language and academics than the latter, but not better adaptive functioning or behaviour problems after follow-up. The group PDD-NOS may have made larger gains than those with autism. Some evidence was provided that intensive treatment may be more effective than parent training, but more research is needed [78].

Drew and colleagues (2002) also conducted a pilot randomised controlled trial of parent training intervention for pre-school children [180]. This trial will not be described here, because there was no diagnose of autism, but they only screened positive on autism. Also two comparative studies were found: First, Eikeseth and colleagues (2002) found at one-year follow- up that children who received intensive behavioural treatment made significantly larger improvements on IQ, language expression and comprehension and communication. This study provides some weak evidence. Second, Salt and colleagues (2002) compared the Scottish early intervention programme (a social-developmental approach) with a control group. Children in the former group improved significantly more on measures of joint attention, social interaction, imitation, daily living skills, motor skills and adaptive behaviour. These results provide some evidence regarding efficacy [165].

Doughty concluded that, based on this primary studies, early intervention may lead to selected gains in a number of specific domains, but further research and replication of studies is required to address the methodological weaknesses [137]. It remains undetermined if early and/or intensive intervention programs are more effective than other treatment programs. The interventions described in this review cover a range of interventions; it was not clear enough that the definition of intensive behavioural treatment, parent training or parent-managed behavioural therapy was uniform over the different studies .

The **review** of McConachie and Diggle (2007) [164]focused on interventions for children aged 1-6 years and was carried out using a systematic methodology. Only studies with a concurrent element of control were included [140], [180], [78, 160, 182] (only studies of the covered period 1997-2007 were mentioned here). Seven articles dating before 1997 were also described in this review. As the study of Aldred and colleagues (2004)[140] is the only one not described in the review, it will be discussed in the further section and the mentioned review of McConachie and Diggle (2007) is therefore excluded based on overlap [164]. Nevertheless, their conclusion was mentioned: it seems that parent training can successfully contribute to intervention for young children with autism spectrum disorders, but improved research is needed.

Aldred and colleagues (2004) **randomised** 28 children with autism spectrum disorders to test a new theoretically based social communication intervention targeting parental communication against routine care alone[140]. The aim was to educate parents and to train them in adapted communication tailored to their child's individual competencies. The treatment group showed significant improvement in reciprocal social interaction and on expressive language, communication initiation and parent-child interaction, compared with the control group.

Howard and colleagues (2005) compared the effects of three treatment approaches on preschool-age children with pervasive developmental disorders in a **quasi-experimental design**. The treatment group received intensive behaviour analytic intervention, the first comparison group received intensive eclectic intervention in public special education, but specifically for autism (for example discrete trial training, sensory integration training, TEACCH) and the second comparison group received a non-intensive public early intervention program. Different standardized tests of cognitive, language and adaptive skills of all children in the three groups were filled out at intake and about 14 months after treatment started. The intensive behaviour analytic intervention group had higher mean standard scores on all domains in comparison with the other two comparison groups at follow up. They conclude that intensive behaviour analytic intervention is more efficacious than eclectic interventions [144].

Cohen and colleagues (2006) also compared early intensive behavioural intervention with special education classes at local public schools. Independent examiners performed IQ, language and adaptive behaviour tests at baseline and 1-3 year follow up. They revealed that the early intensive behavioural intervention group obtained significant higher IQ and adaptive scores than the comparison group. For language comprehension and non verbal skills, no significant differences were found. A closely resembling study is this from Magiati and colleagues (2007). In this prospective study, the outcome for preschool children with autism spectrum disorders was compared, receiving autism-specific nursery provision or home-based Early Intensive Behavioural Intervention.

Both were applied in community settings. Both groups showed improvements but standard scores changed little. At follow-up (2 years after the intervention), there were no significant differences in cognitive ability, play, language or severity of autism. The only difference was the for the Vineland Daily Living Skills standard scores, this in favour of the Early Intensive Behavioural Intervention Group. They found large individual differences in progress. IQ and language level seemed the best predicting variables. The authors concluded that both interventions produced comparable outcomes after two years of intervention [145].

Based on Howard and colleagues (2005) and Cohen and colleagues (2006), it can be suggested that early intensive behavioural intervention can be effective when it is delivered in more typical community settings and when it is compared with treatment as usual for children with pervasive developmental disorders [142, 144]. However, these researchers did not consider the following questions: First, does early intensive behavioural intervention have an impact beyond the cognitive, language, and adaptive behaviour deficits associated with autism spectrum disorders, additionally affecting the characteristic diagnostic symptoms of the disorder? Second, what is the impact of early intensive behavioural intervention on the parents? These research questions are well described by Remington and colleagues (2007). This study did not meet the Cochrane criteria (2/9) for quasi-experimental designs, but has good scores on Gersten (13/14). It is a 2-year **controlled comparison study** of early intensive behavioural intervention compared with treatment as usual within the United Kingdom. Data shows a positive advantage for the intervention group: the effect size for the impact of the intervention on the children participating was substantial and clinically meaningful at the group level. Parental well-being showed no evidence that behavioural intervention created increased problems [147].

It has to be remarked that in the four abovementioned studies ([142, 144, 145, 147]), children were not randomised into groups, but the division was based on the preference of the parents. This is an important shortcoming of these studies.

Eldevik and colleagues (2006) [143]compared 2 groups of children receiving behavioural treatment or eclectic treatment (at least two of the following intervention types: alternative communication, applied behaviour analysis, total communication sensory motor therapies, programs based on TEACCH or methods based on the personal experiences of the particular teacher). It is important to notice that they combine a relatively small amount of one-to-one behavioural treatment (fewer than 20 hours per week) and placement with other peers, this in contrast to the abovementioned studies.

After 2 years of treatment, the behavioural group made lager gains than the eclectic group on most areas (intellectual functioning, language comprehension, expressive language and VABS communication). But gains were more modest that those reported in the previous studies ([155]; [78]. Possible explanations could be a lower IQ score in pre-treatment or the low number of treatment hours in the present study. The study of Eikeseth and colleagues (2007) [156] is in line with Eldevik and colleagues (2006) [143]. Because the number of participants is higher in the latter, the study of Eikeseth and colleagues (2007) [156] is excluded based on overlap.

Sallows and Graupner (2005) **randomly assigned** children with autism to a clinic-directed group and a parent-directed group in their outcome study. In the clinic-directed group, they replicated the parameters of early intensive behavioural treatment. The parent-directed group received less hours of supervision than the clinic-directed group. After the combination of both groups, the researchers found that 48% of all children with autism showed rapid learning, achieved average post-treatment scores and were succeeding in regular education classrooms at age 7. Pre-treatment imitation, language and social responsiveness were the best outcome predictors for treatment. Parent-directed children did about as well as clinic-directed children, although they received much less supervision [148].

Parent training and pivotal response training (PRT)

Description of the intervention

The following study of Stahmer and Gist (2001) taught the parents of a child with an autism spectrum disorder, the naturalistic technique called 'pivotal response training' (developed by Koegel in 1987). They adapted the program to focus on increasing parent's ability to facilitate play and language skills in their young children with autism spectrum disorders.

They assessed the addition of a parent education support group to an accelerated parent education program. Both groups received individualized parent education for 12 weeks, and one group also attended a weekly parent education support group. This study had a twofold aim: first to assess the effectiveness of an accelerated parent education program and second, to examine the effects of providing disorder specific support and information to parents participating in a parent education program. The parent education content consisted of several strategies which the parents learned to increase the motivation, including: formulating clear instructions and questions, intersperse maintenance tasks, giving opportunity to the child's choice with shared control, using direct and natural reinforcers and using reinforcement of attempts. The content of the parent information support group consisted of a variety of topics relevant to autism spectrum disorders, but did not include discussion of PRT techniques. For example diagnostic issues and challenges and opportunities with siblings were discussed [151].

Evidence of the intervention

The results of the study from Stahmer and Gist (2001) indicated that a parent education support group in a parent education program may increase the mastery of parents to teach techniques and success of accelerated programming and increases the children's language success. Although parents in both groups learned the techniques, the parents who also participated in the information support group were more likely to master the techniques at a higher level. Possible explanations are supplied: the discussion of PRT techniques helped them to better understand these techniques, the support group could have been served as a respite function so parents were better able to focus on learning PRT techniques during the education sessions, the additional support increased

their understanding in the importance of the educational process and/or families could have learned about additional community resources which they accessed during the training [151].

Developmental, Individual Difference, Relationship model

Description of the intervention

The developmentally oriented approach is drawn from a developmental model of autism and is interdisciplinary organized. Disciplines involved are speech and language therapists, psychologists, occupational and special education therapists. Family consultation is also very important in this program. The DIR (developmental individual-difference relationship intervention) of Greenspan uses three learning principles: (1) following the child's lead and engaging in child-mediated interactions, based on the child's natural emotional interests; (2) semi-structured problem-solving interactions that meet specific language cognitive and social goals and (3) motor, sensory and spatial learning activities [139] .

Evidence of the intervention

Zachor and colleagues (2007) compared the impact of two comprehensive approaches. The first is an eclectic-developmental approach, mostly based on the developmentally oriented philosophy and the DIR model, and incorporated also various other methods from the TEACCH and applied behaviour analysis (ABA) as well. The other intervention was based solely on ABA and its curriculum included DTT, naturalistic and incidental teaching techniques. Both interventions were centre-based. In the measured domains (language, communication and reciprocal social interaction), the ABA group improved more than the eclectic-developmental group.

After 1 year, change of diagnostic classification was significantly higher for the ABA group than for the eclectic-developmental group [139].

Teacher training in applied behaviour analysis

Evidence of the intervention

Reed and colleagues (2007) studied the effectiveness of 3 early teaching interventions, namely applied behaviour analysis, special nursery placement and portage for children with autism spectrum disorders. The intensity of the intervention was different for these 3 intervention groups. In this study they found that children in the ABA group made greater intellectual and educational gains than children in the portage group and they made greater educational gains than children in the nursery program. Children in the nursery program made larger gains in adaptive functioning than the children in the portage group. The fact that ABA has a strong impact on intellectual and educational gains and special nursery on adaptive behaviours could be explained by the different teaching approaches (one-to-one for ABA and in group for special nursery). The authors state that this pattern could lead to the suggestion that any program should include both one-to-one work, followed by group work [146].

Cognitive Behaviour Therapy (CBT)

Description of the intervention

Cognitive Behaviour Therapy (CBT) is based on the theory that behavioural and psychological problems arise as a result of cognitive deficiencies and distortions. The aim of CBT is to identify and to correct these deficiencies and distortions. The typical components of CBT are (a) assessment of the problem; (b) affective education (to illustrate the connection between deficiencies and distortions of thinking, affect, and behaviour); (c) cognitive restructuring (to challenge dysfunctional thinking in a logical way and implement more healthy ways of thinking); (d) stress or anxiety management; (e) self-reflection (to improve insight into thoughts) and (f) practice of the principles learnt in everyday situations (White, 2004).

We have to remark that CBT is possible for people (children) with autism spectrum disorders, particularly for people with the syndrome of Asperger, but is not suitable for very young children or lower functioning children. A minimum level of cognition is required to allow appropriate interaction (White, 2004).

CBT is usually performed by a trained therapist and can be organized in individual or in group sessions. Sometimes, parents and teachers act as co-therapists (White, 2004).

Evidence of the intervention

The review of White (2004) describes the studies of Sofronoff and colleagues (2003) and Bauminger (2002) [183, 184]. The study of Bauminger (2002) was excluded based on screening full text because no control group was implemented. Because we found more recent publications of the study of Sofronoff and colleagues, namely from 2005 and 2007, the review of White (2004) was excluded based on overlap [170].

Sofronoff and colleagues (2005) evaluated the effectiveness of a brief CBT intervention for children with Asperger Syndrome by **randomly assigning** children to three conditions: intervention for the child only, intervention for the child and parent and a wait-list control group. The two intervention groups demonstrated a significant decrease in parent-reported anxiety symptoms at 6-weeks follow-up and a significant increase in the child's ability to generate positive strategies. The intervention was also endorsed by the parents as a useful programme for their children. The parents also indicated that a high level of parental involvement was preferred [149]. The more recent CBT-study of Sofronoff and colleagues (2007) took this preference into account. In this study they **randomly assigned** children with Asperger Syndrome in two conditions: a brief CBT-intervention group (six 2-h weekly sessions) and a wait-list-control group. Parent reports also indicated a significant decrease in anger and a significant increase in their own confidence in managing anger in their child. They indicated some generalization of strategies learned in the clinic setting to home and school settings [150].

A **randomized controlled trial** was applied by Chalfant and colleagues (2007) (Chalfant, Rapee, & Carroll, 2007). They assigned children with comorbid anxiety disorders and High Functioning autism or Asperger Syndrome to a family-based, cognitive, behavioural treatment group or a waiting-list condition. They found that 71.4% of the treated children no longer fulfilled diagnostic criteria for an anxiety disorder in the treatment group and they found significant reductions in anxiety symptoms as measured by self report, parent report and teacher report in the intervention group, compared with the waiting list group

Conclusion

The abovementioned studies failed to note any evidence of 'recovery' from autism produced by early intervention or allied behaviour analysis as Lovaas claimed in 1987. At this moment, more sober conclusions could be drawn: the principles of applied behaviour analysis *could be an important element in* any intervention program for children with autism spectrum disorders. Strictly, it is impossible to compare the abovementioned studies directly because a number of factors are related to the outcome, for example IQ at intake, duration of treatment, used measures for outcome, staff training and the level of supervision. Most of the studies compared behavioural treatment interventions to eclectic, school-based, non-specified or no treatment interventions, mostly suggesting the behavioural intervention to be more effective than the other intervention. Thus, these studies are suggesting some evidence regarding general behavioural interventions, but due to a lack of similarities in the intervention methods no clear proposition could be postulated.

3.3.2.5 General early and comprehensive interventions

Introduction

Comprehensive interventions (a) address all problem behaviour performed by a child, (b) are driven by the functional assessment outcomes, (c) are applied across all (or an extent part) of the child's day, (d) typically incorporate multiple intervention procedures and (e) fit the context where they are implemented.

Comprehensive treatments stand in contrast to research-based interventions which often focus on a narrow response pattern in a limited context over short instructional sessions. Comprehensive interventions are designed to meet the more expansive expectations and needs of teachers, families and children with autism. [185]; [173, 186].

This part focuses on 'parent management training' and on the 'Early Social Interaction Project'. Interventions like pivotal response training, discrete trial training, Developmental, Individual Difference, Relationship model (DIR) and integrative therapies could also be described here, but they were mentioned earlier.

For this part of the review, 4 articles were found. From these articles, 2 articles were approved and therefore included in this part of the review [187, 188], 1 article was excluded based on quality criteria [179] and 1 article was excluded based on overlap [189]. More detailed information about the evidence is listed in the summary of findings table for general early and comprehensive interventions (see Appendix to Chapter 3).

Parent management training

Description of the intervention

Parent management training is a popular form of therapy aimed to encourage parents to become actively involved in interventions that strengthen family functioning. Parent management training in the study of Sofronoff consists of psycho education, comic strip conversations, social stories, management of rigid and problem behaviour, routines, special interests and anxiety management. Comic Strip Conversations and Social Stories were developed by Gray [190-192]. Comic strip conversations were based on the notion that the provision of visual supports and visualization might improve the understanding of conversations and social comprehension of children with Asperger syndrome and is in line with Social Stories which addresses the child's inability to detect and appropriately interpret the subtle cues in social situations, to understand another person's perspective and to behave in socially appropriate ways. A Social Story is a brief personalized story that provides information in relation to a specific situation.

Evidence of the intervention

Sofronoff and colleagues (2004) implemented a **controlled trial** of parent management intervention to increase the parental competence in management of problem behaviours associated with Asperger Syndrome. They compared three formats: a 1 day workshop, individual sessions and a waiting-list control group receiving no intervention. They concluded that parent management training can be an effective intervention for parents with a child with Asperger syndrome. Parents indicated significant improvement following parent training for both intervention groups on each of the measured outcome variables, number of problem behaviours, intensity of problem behaviours and ratings of social skills whereas the waiting list control group showed no significant improvement on any of the outcome variables. In addition to this they found some notable differences between the workshop group and the individual session group on the outcome variables. The measure of parent ratings of the intensity of problem behaviours revealed a significant difference between the intervention groups at 4 weeks and at three months follow-up, with the parents in the individual session group reporting greater change. The workshop group was not significantly different from the waiting list group at these two times [187].

Early Social Interaction Project

Description of the intervention

The Early Social Interaction (ESI) Project is a parent-implemented intervention in a natural environment, using an individualized curriculum. Parents identify family routines and activities which are important for them and their child and which will be the context for the intervention. The focus is on social communicative skills. Care providers teach skills to the parents and learn them to create moments to implement those specific intervention techniques within everyday routines [188] .

Evidence of the intervention

Wetherby and colleagues (2006) compared an ESI group who entered at age 2 years with an ESI group who entered at age 3 years. The results showed significant improvement on 11 of 13 social communication measures. The results of the group who entered at age 2 years were comparable to the other group on communicative means and play, although they showed significantly poorer performance on other social communication measures [188].

Conclusion

'Parent management training' and the Early Social Interaction Project' were studied in depth. Insufficient evidence was found to support the effectiveness of these particular interventions. More adequate research is needed.

3.3.2.6 Specific interventions

Introduction

In this part, we focus on specific interventions for children with autism spectrum disorders, namely massage therapy, concept mapping and occupational therapy incorporating animals. Other interventions like daily life therapy, psychotherapy, client centred therapy, system therapy, son-rise program and wonder and alternative therapies (for example dolphin therapy, holding therapy, gluten casein free diet and Bachflower therapy) are also perceived under this category but no articles of good quality criteria were found for these interventions. This also means that they could not be perceived as evidence based treatment methods. For this part of the review, 5 articles were found. From these articles, 1 article ([193]) was approved and therefore included in this part of the review and 4 articles ([194]; [195-197] were excluded based on quality criteria. More detailed information about the evidence is listed in the summary of findings table for specific and other interventions (see Appendix to Chapter 3).

Massage or touch therapy

Description of the intervention

In the following study of Field and colleagues (1997) applied touch therapy in children with autism spectrum disorders. Children were fully clothed and their entire body was rubbed using moderate pressure and smooth stroking movements on each of the following areas: head/neck, arms/hands, torso and legs/feet [193].

Evidence of the intervention

Field and colleagues (1997) **randomly assigned** 22 children with autism spectrum disorders to a touch therapy or a touch control group. Both groups received 8 therapeutic sessions, wherein children in the touch group their body was rubbed using moderate pressure and smooth stroking movements, children in the touch control group did a game with a student volunteer in a game selecting different colour/form/shape toys. Results revealed that touch aversion and off-task behaviour decreased in both the touch therapy and the touch control group. Orienting to irrelevant sounds and stereotypic behaviours decreased in both groups, but significantly more in the touch therapy group. We need to remark that no follow-up was measured in this study, so no generalization was measured [193].

The articles from Hartshorn and colleagues (2001) [195] and Escalona and colleagues (2001) [194] were excluded based on quality criteria. In these studies, parents give massage therapy to their children or tell stories to them. But no element was used to control if this was provided conform the research protocol.

Concept mapping

Concept mapping is an educational tool, based on the principles of constructivism. This includes the premise that learning is an active process and the learner must select, manipulate and transform information in order that meaningful learning could occur. In concept mapping, individuals construct a visual map that represents their knowledge on a topic and also shows how new information relates to their existing network.

This study of Roberts and Joiner (2007) was excluded due to no take into account the differences between the IQ in the control group and in the experimental group and no description of the way of assigning to groups. Therefore, this study, scoring 1 out of 10 on the Cochrane criteria and 6 out of 14 on the Gersten criteria, was excluded [196].

Occupational therapy incorporating animals

Therapy incorporating animals are based on the assumption that children exhibit a natural interest toward animals (Sams et al., 2006). In the intervention from Sams and colleagues children were encouraged to train llamas to compete in an obstacle event in a biannual 'llama show', but this study did not meet the quality criteria of Cochrane and Gersten and were therefore excluded [197].

Conclusion

Several non-traditional treatments (massage or touch therapy, concept mapping and occupational therapy incorporating animals) for children with autism spectrum disorders have been reviewed above, but no single treatment modality has been shown to be evidence-based. More adequate in depth research is needed.

3.3.2.7 General reviews

Next to the abovementioned six specific categories defining articles with treatments for children with autism spectrum disorders, 3 general reviews [198];[199, 200]) were found concerning an overview of the overall treatment for these children. They can be described as 'narrative reviews' and were not included because they did not meet the quality criteria for systematic reviews from Cochrane.

3.3.3 General conclusion

Despite the relatively large volume of studies published about the effectiveness of interventions for children with autism spectrum disorders, only few studies met the predefined selection criteria. Randomized controlled trials, under idealized conditions, provide the strongest evidence of the efficacy of an intervention, but only a few were found concerning psychosocial treatments for children with autism spectrum disorders. The paucity of randomized controlled trials in the area of autism reflects the experienced difficulties: in contrast to drug trials, where patients and the physicians are blind to the intervention condition, in psychosocial treatments parents and therapists are well-aware of the treatment condition that their children will receive. Moreover, ethical difficulties with random assignment are a well-known problem in this area. Evaluations of most interventions rely mainly on single subject or case series studies or on non-randomised group trials. Nevertheless, since the pathophysiology of autism is not known yet, it seems to be reasonable to be careful when implementing on a large scale treatments based on their results in single-subject studies. Single-subject studies might have been involving a certain subtype of autism; whereas the possibility of bias in case-series or non-randomised group trials is well-known. Since this study aims at advising the Belgian government on how to implement therapy for all patients of the whole country, it seems reasonable to do so starting from the highest level of evidence.

In addition to this, it is very difficult or even impossible to compare the abovementioned studies due to different IQ and severity of autism spectrum disorders at intake, duration of treatment, used measures, staff training, level of supervision… Therefore it would not be correct to state one of the mentioned interventions as 'the' method to treat or even cure autism spectrum disorders. Given the heterogeneity of pervasive developmental disorders and the knowledge that there is no single known aetiology, it seems also unlikely that any single cure will be found.

In this review, the interventions for pervasive developmental disorders were divided into six different categories: three categories following the classic triad of treatment, namely: 'interventions for social interactions', 'interventions for language and communication' and 'interventions for restricted, stereotyped, repetitive repertoire of interests and activities' and further three general approaches, namely 'general behavioural interventions', 'general early and comprehensive interventions' and 'specific and other interventions'. Little (imitation sessions and joint attention training) or no (social skills training, specific multimedia and Lego© therapy) evidence was found

concerning the 'interventions specially created to improve the social interactions' for children with autism spectrum disorders.

Concerning 'interventions for language and communication', the Picture Exchange Communication System can provide one effective element of a wider 'eclectic' treatment method, although the failure of treatment effects to maintain suggests that another ongoing intervention is likely to be required. Insufficient evidence was also found to support the effectiveness of using 'music therapy' and 'auditory integration training' regarding the 'interventions for restricted, stereotyped, repetitive repertoire of interests and activities'. The studies concerning behavioural treatment methods failed to confirm the claim of 'recovery' from autism produced by early intervention or applied behaviour analysis (Lovaas, 1987). A more realistic conclusion could be drawn from the selected articles: the principles of applied behaviour analysis *could be an important element in* any intervention program for children with autism spectrum disorders. Insufficient evidence was found to support the effectiveness of the interventions 'Parent management training' and the Early Social Interaction Project' in the chapter 'general early and comprehensive interventions'. Finally, several non-traditional treatments (massage or touch therapy, concept mapping and occupational therapy incorporating animals) for children with autism spectrum disorders have been reviewed above, but no single treatment modality has been shown to be evidence-based. In general and across the different superficial categories, it can be concluded that more in depth and improved research is needed. Future studies about the effectiveness of interventions for children with autism spectrum disorders must use widely recognized standardized tools, have sample sizes large enough to generate a certain degree of statistical power and include a long-term follow up.

By searching the different databases, no articles were found concerning the effects and differences between mono- and multidisciplinary treatment. In the included studies, treatment interventions were done by a researcher. Therefore, no conclusions could be formulated about the evidence of the kind and the number of disciplines needed to be incorporated to deliver evidence-based psychosocial treatments. It is also remarkable that no statements could be made about the effectiveness of treatment in comorbid disorders. The included studies only investigated psychosocial treatments within children with the only diagnosis 'pervasive developmental disorders'. The co-existence of other comorbid disorders was not mentioned in the description of the subjects in the included studies. This is noticeable because comorbid disorders are widespread. More research is needed concerning these topics. The mean age of the participants in the included studies is about 4 to 4.6 years; therefore conclusions about the effectiveness of these psychosocial treatments could only be generalized for this age group.

To conclude, some general principles seem to be promising concerning psychosocial treatments in children with pervasive developmental disorders:

First, a single modal intervention seems not the appropriate way. The complex difficulties regarding autism spectrum disorders probably require a multi-modal intervention approach including parent support and a child-directed component. Behavioural and educational interventions became a dominant approach for treating children with autism spectrum disorders. It could be argued that the principles of applied behaviour analysis could be included as an important element in the intervention programs for these children. It is also important that parents are actively involved in the intervention process. Through this, the interventions help to support families in caring for the child and being more aware of the experienced problems of their child, they help the family to use the intervention strategies in their daily routines and by doing so making generalization of the learned skills possible. Second, it seems important to identify children with autism spectrum disorders as early as possible and to start appropriate interventions. Early intervention speeds the child's overall development and reduces inappropriate behaviours. Third and final, interventions seem to be individualized and based on the strengths and needs of the child and his family.

Future evaluation must consider which components of these interventions could be combined in a logical way to provide effective 'eclectic' methods of care for children and their families.

3.3.4 Discussion

In clinical guidelines, findings from evidence-based literature are translated into practical advice. The findings from this review were compared with the below mentioned recent clinical guidelines:

- "The Clinical Practice Guideline: Report of the Recommendations for Autism and Pervasive Developmental Disorders - Assessment and intervention for young children (age 0-3 years)" from the New York State Department of Health (1999).
- "The identification, assessment, diagnosis and access to early interventions for pre-school and primary school children with ASD" from the National Autism Plan for Children (NAP-C) (Le Couteur, 2003).
- "Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders" from the Scottish Intercollegiate Guidelines Network (SIGN, 2007).
- "The New Zealand Autism Spectrum Disorder Guideline" (2008).

In general, no real inconsistencies were found between the findings from the review and the abovementioned clinical guidelines. In addition to this, the guidelines provide us with some essential complementary conclusions which will be formulated beneath.

"The Clinical Practice Guideline: Report of the Recommendations for Autism and Pervasive Developmental Disorders - Assessment and intervention for young children (age 0-3 years)" describes next to the general, behavioural, educational and experiential approaches for children with pervasive developmental disorders also medication and diet therapies, which were not in the scope of this review. Other conclusions in this guideline are comparable and in line with the review.

The guideline from Le Couteur (2003) formulates the following supplementary conclusion: "Pre-school children should have access to 15 hours per week of appropriate 'pervasive developmental disorder'-specific programmes. A pervasive developmental disorder-specific intervention does not necessarily imply segregated pervasive developmental disorder provision nor 1:1 working (this finding is based on well conducted clinical trials but not on randomized clinical trials)." Any other identified problem should be addressed, this may involve liaison with other specialist services.

The SIGN guideline also concluded that no evidence was identified to indicate whether a particular model was more effective in improving outcomes. There is a need for multiagency involvement taking into account that the competencies of those professionals are more important than their professions as such.

The "New Zealand Autism Spectrum Disorder Guideline" provides us with the following conclusion interesting in the scope of this study: "There is debate about whether the behavioural, emotional and mental health issues of people with pervasive developmental disorders should be considered co-morbid disorders (i.e. completely separate disorders that occur at the same time as pervasive developmental disorders) or underlying symptoms of pervasive developmental disorders itself. Nevertheless, international guidelines for children with pervasive developmental disorders suggest that treatment of pervasive developmental disorders itself should be distinguished from treatment of co-morbid disorders and treatment should be individualised. While no treatment or medication actually cures pervasive developmental disorders, such interventions can sometimes effectively manage associated emotional and mental health problems".

3.4 SPEECH, LANGUAGE AND LEARNING DISORDERS

3.4.1 Introduction

The search strategy for evidence-based treatment methods for speech, language and learning difficulties was generated as a whole, without making the distinction between speech and language difficulties and learning difficulties, proved to be very effective. A total of 240 potentially appropriate studies were found searching the different databases. Of these, 12 studies could not be retrieved [201;202; 203;204-211]. As some of these studies did not provide the necessary information concerning research design, total number of participants, presence of a control group, lack of clearly described interventions … a total of 166/240 studies were excluded based on screening of the full text.

From the remaining 74 studies, 10 studies were excluded due to overlap with the review of [212; 213;214;215;216, 217; 113, 218-221] and 15 studies were excluded based on the defined quality criteria [222;223;224; 205, 225-235] (see Appendix to Chapter 1 for an overview of the exclusion criteria). The 48 remaining studies proved to be appropriate to be included in the review. An overview is provided in the flow of the search strategy of articles dealing with evidence-based treatment methods for language and speech difficulties and learning difficulties in Appendix to Chapter 3.

3.4.2 Speech and language disorders

3.4.2.1 Introduction

Although studies report different percentages of prevalence, it is thought that on average approximately 6% of children may have speech and language difficulties (Boyle, McCartney, Forbes, & O'Hare, cited in [212] In literature, there is little consensus concerning the aetiology of primary language delay/disorders but the impact of those difficulties can significantly influence the individual, family and society in short and in long term.

Regarding aetiology there is widespread agreement on multiple risk factors like genetic factors, socio-economic status, difficulties in pregnancy, chronic otitis media and oral-motor difficulties. Implications of speech and language difficulties involve problems in school achievement and can be associated with social, emotional and behavioural problems. The problems can hold long-term difficulties that persist in adolescence and beyond. Therefore interventions can vary widely and take many forms. Intervention can be performed in different environments (school, home, clinic) and can be direct (focus on treatment of the child) or indirect (adults in the environment of the child facilitate communication). Treatment can be aimed at improving receptive language or expressive language. There is little consensus about the duration of treatment. Therapy can be long and intensive but also short-time interventions and less intensive interventions exist [212].

3.4.2.2 Evidence-based interventions for speech and language disorders

Introduction

As described in the methodology, an existing systematic review of good quality, concerning evidence-based treatment methods of language and speech difficulties was used as the basis for the literature review of this part of the study and further updated if necessary. The following review about the evidence-based treatment methods for language and speech difficulties is to a large extent based on the Cochrane review of [212]. Since it includes all studies up to 2002, all studies concerning evidence-based treatment methods for language and speech difficulties before 2002 were excluded. The literature from that point on will be discussed. For that part of this review, 13 articles (and 1 review) were included [212, 236;237;238, 239;240-242;243; 244-247]and [248]. Detailed information concerning the evidence is provided in the summary of findings table for speech and language disorders (see Appendix to Chapter 3). This table contains information regarding subject characteristics, sample size, type/duration of intervention, therapeutic speciality(ies), purpose of intervention, used method of effect evaluation, reported effects (effect sizes) and study quality.

Evidence: A Cochrane review

Law and colleagues (2003) published a high quality Cochrane review concerning the effectiveness of speech and language interventions for children and adolescents with primary speech and language delay/disorder. This review considered randomised controlled trials of speech and language therapy interventions. The included interventions, concerned any type of intervention to improve expressive or receptive phonology (production or understanding of speech sounds), expressive or receptive vocabulary (production or understanding of words), or expressive or receptive syntax (production or understanding of sentences and grammar). Speech and language therapies were compared to delayed or no treatment conditions, to general stimulation conditions and to other speech and language therapy approaches.

Outcome was measured including formal standardized tests, criterion referenced tests, parent report and language samples and were dependent on the focus of the intervention (semantics, syntax or phonology).

The review consists of 33 trials of which 25 studies included sufficient data to be used in the meta-analyses.

The authors concluded that speech and language therapy interventions may be effective for children with expressive phonological (SMD=0.44, 95%CI: 0.01, 0.86) and expressive vocabulary difficulties (SMD=0.89, 95%CI: 0.21, 1.56). The effectiveness of expressive syntax interventions showed mixed findings (n=233; SMD= 1.02, 95 % CI: 0.04-2.01). Less evidence was found for the effectiveness of the interventions for children with receptive difficulties (SMD=-0.04, 95%CI: -0.64, 0.56). Evidence suggests that therapy can be effective when no receptive difficulties exist together with those expressive difficulties. The found evidence suggests that the effect of therapy on language outcome is much smaller for children with receptive difficulties than for other difficulties.

Studies concerning different approaches of expressive language intervention did not show significant differences between interactive and directive approaches but some research suggests that higher functioning children and children with learning disabilities benefit more from interactive learning and children with more severe difficulties but normal intelligence benefit from directive learning [212].

There were no differences found between the use of trained parents and clinicians as the administrators of intervention (SMD=0.01, 95% CI: -0.26, 1.17). Possibly the use of parent administrators evokes a more varied response to treatment because some parents are more suited to parent treatment than others ([214]; [249]a). The included studies did not show significant differences between group therapy and individual treatment (SMD=0.01, 95 % CI: -0.26, 1.17) but involving normal language peers in therapy has a positive effect on therapy outcome (SMD=2.29, 95% CI: 1.11, 3.48).

A limitation of this review is that analysis did not include second-order effects of therapy. Most of the reported interventions are limited to interventions in the context where children learn (early year provision and school) and are vague in terms of intensity and duration of treatment. Most of the children with speech and language difficulties receive more interventions than only speech and language therapy and this can also have an effect on outcome. In terms of duration of therapy researchers rarely include a measure of long term follow-up and the question arises if the effects of therapy maintain over time. Sommers and colleagues (1964 as cited in Law et al., 2003) reported gains in phonology measures four months after therapy but Almost and Rosenbaum (1998 as cited in [212]) reported only maintenance of gains four months after the intervention. Robertson and Weismer (1999) [219] and Fey and colleagues (1997) [214]reported, in terms of expressive language gains, maintenance respectively three and five months after the intervention, although [250] reported that the effect of therapy had worn off six months after the intervention. This review holds a large degree of variation in the included studies (mostly for the expressive language interventions) due to different administrators of therapy and differences in response due to socio-economic status, comprehension levels, duration and intensity of treatment. There is a need for more homogeneous research that defines interventions procedures better and controls the participants' characteristics more closely.

Evidence: A Health Technology Assessment (HTA) report

A good quality HTA report concerning speech and language therapy for primary school-age children with persistent primary receptive and/or expressive language impairment was published in 2007. Boyle and colleagues (2007) examined direct versus indirect and individual versus group modes of speech and language therapy [236]. An overview of the quality criteria is provided in Appendix to Chapter 3. Secondary, they investigated the long-term effects of therapy at 12 months' follow-up. Finally, they looked for the cost-effectiveness of the involved therapies.

In the HTA report, literature concerning the effectiveness of individual therapy versus group therapy provides us with little evidence found for children with language difficulties between 0 and 7 years.

Boyle and colleagues (2007) [236]refer to the abovementioned systematic review, carried out by Law and colleagues (2003) [212]. Three randomized controlled trials met their inclusion criteria but the findings revealed no differences between group and individual therapy in the outcome for articulation (Sommers, Schaeffer, Leiss, Gerber, Bray, et al., 1966 as cited in [212]), no differences in outcome for expressive vocabulary [251] and Barrat and colleagues (1992) revealed that intensive individual therapy yielded greater gains in expressive language than a once-weekly session of group therapy, but no differences for receptive language [252]. Boyle and colleagues (2007) reported that for children between 6 and 11 years, intervention studies reveal the effectiveness of both individual therapy [236]; [253-255] and group therapy ([256-258]. Boyle and colleagues (2007) concluded that there was no significant difference in outcome between individual and group therapy [236].

The question whether direct therapy is more effective than indirect therapy was addressed in the systematic review of [250]. Three studies examining expressive language outcome revealed no difference in outcome between clinician-administered and parent-administered intervention ([259]; [260];[249]).

Nye and colleagues (1987) [212]came to the same conclusion in their meta-analyses. Boyle and colleagues (2007) prevailed in their trial that there were no differences in outcome for direct versus indirect therapy. Administers of therapy, different than the speech-language therapist, who received training, are proven to be useful in therapy and therefore need more research [236].

Boyle and colleagues (2007) confirmed findings from previous research [113, 212, 250] that there were no significant differences in receptive or expressive language outcomes between individual and group therapy and between direct and indirect therapy. The trial also confirmed that intervention is more effective in outcome for expressive language than for receptive language. This holds the same result as Law and colleagues (2003) that showed that outcome is more effective when children do not also have receptive language problems [212]. Because little research is carried out to evaluate outcome of receptive language only, an extra literature search was done. Boyle and colleagues (2007) found only two published controlled studies that prevailed receptive language gains in preschool children ([217]; [113]. They confirmed that receptive language difficulties should be more intensively investigated in the future. Because the trial of Boyle and colleagues (2007) included evidence based therapies, the receptive language problems were hardly included in the therapy manual. Interventions concerning comprehension, clarification, understanding of the meaning of words, grammar and narrative sequences with the purpose to alter language comprehension scores did not show significant gains in comprehension and show the need for further research of effective interventions for children with a receptive component to their language difficulties [236] .

The question whether intensive therapy is more effective is under-researched. Boyle and colleagues (1995) showed that more intensive therapy showed significant effects in outcome whereas less intensive therapy did not show a significant effect [261]. Similar results were reported by Boyle and colleagues (2007) proving that an intervention delivered three times a week for 30-40 minutes over a 15 week period yielded significant improvements for expressive language but not for receptive language [236].

Long term outcomes of speech and language therapy were seldom researched in literature. Fey and colleagues (1997) [214]reported maintenance of progress 5 months after the intervention but Law and colleagues (1998) reported the loss of effect 6 months after the intervention [250], just like Whitehurst and colleagues (1991) who reported the washout of progress 3 years after the intervention [262]. Boyle and colleagues (2007) found that 15 weeks of intensive intervention resulted in short-term improvements compared to controls, but there was no evidence of long-term benefits of the project therapy 12 months after the intervention. They suggest a longer time of intensive therapy to achieve more lasting benefits of therapy [236].

The last research question, concerning the costs of therapy identified indirect group therapy, as the least costly and the direct individual therapy as the most costly option [236]. These findings can not be interpreted as providing information about cost-effectiveness of interventions because the results of this trial do not give enough significant results concerning effectiveness of interventions.

Although Law and colleagues (2003) concluded that there were no differences in outcome found between the use of trained parents and clinicians as administrators of intervention, Gibbard and colleagues (2004) concluded the opposite [212, 237]. This study was found qualitative good enough to be included in this review. They compared a parent-based intervention (PBI), where parents learned techniques to stimulate and develop their child's language, with a general care intervention for preschool children with expressive language delay. Parents in the PBI received information about linguistic goals and practice demonstrations whereas parents in the general care got general advice concerning techniques to stimulate language development. They concluded that the parent-based intervention had significantly better outcome than the general care intervention. A possible explanation could be a different profile of the parents giving the interventions. Some parents may be better in providing parent treatment than other parents.

Whereas the abovementioned review [212] and the HTA report [236] discussed the evidence-based interventions for language and speech disorders in general, the following chapters will be divided by kind of intervention implemented by the researchers. In literature, phonological, grammatical, lexical, pragmatic and interventions focussing on multiple levels of language are found. Due to the high demanding quality criteria as described in the methodology, 7 studies were preserved for phonological intervention, 1 study for grammatical intervention and 2 studies for lexical interventions.

Evidence: Phonological intervention

Reading failure is seen as largely influenced by the knowledge of spoken language. Stackhouse and Wells (1997 in[238]) claimed that the child's awareness of the sound structure of spoken language- referred to as phonological awareness (PA)- holds a crucial link between spoken and written language. Children with speech/ language and reading difficulties often experience problems in riming, blending of sounds, deleting sounds in words and segmentation of words. Phonological awareness interventions involve activities that increase the knowledge about the sound structure of words and include tasks that demand knowledge of the connection between speech and writing [239]. Through accurate word-decoding abilities, children learn to improve their reading performances. It is important to understand how improvement in spoken language affects the written language system. How do children with spoken language impairment benefit from PA intervention and improve their reading and spelling abilities?

Having read the articles focussing on phonological interventions and after judging them for overlap with the review and HTA report, 6 studies were found meeting the inclusion criteria [240-242; 243; 244, 245]. This number was augmented by two other articles ([238, 239]) that were not included in the review of Law and colleagues, but seems to prove relevant to be included in this review.

Gillon (2000) prevailed that children with speech and language impairments benefit significantly from a phonological awareness intervention. The 61 children were divided in 3 intervention groups (a group that received phonological awareness intervention, a group that received traditional intervention and a minimal intervention control group) and a control group with 30 typically developing children.

The phonological awareness intervention consisted of two, 1 hour individual sessions per week until a total of 20 hours of intervention was completed.

The intervention covered skills like rhyme, phoneme manipulation of sound in isolation, phoneme identity, phoneme segmentation, blending, and activities that linked speech to print. The study showed the significant effect of phonological awareness training on improving the phoneme awareness, speech production, reading accuracy and reading comprehension skills of children with speech and language impairments. The conclusion can be drawn that pre-school children with speech and/or language delays can benefit from phonological awareness training [238].

Gillon (2002) reports the follow-up data of the effectiveness of the Gillon Phonological Awareness Training [238a,b] for children with spoken language impairments (receptive language impairments were excluded) who demonstrated early reading delay. Gillon (2002) demonstrated that intervention focussed on development of children's knowledge of the sound structure of spoken words through phoneme identity, phoneme segmentation and phoneme manipulation tasks, and the knowledge of phoneme-grapheme connections results in significant gains in reading abilities 11 months after post-intervention assessment. Phonological awareness intervention results in long-term benefit compared to other treatments [239].

As children with expressive phonological impairments meet problems of poor underlying perceptual knowledge of the sound system (identification of correct and incorrect exemplars of commonly misarticulated words), Rvachew and colleagues (2004) studied the benefits of a perceptual approach to treat expressive phonological delay.

In addition to regular language and speech therapy, 34 children between 41 en 62 months with expressive phonological delays, received 16 treatment sessions. The group receiving training in phonemic perception, letter recognition, letter-sound association, and onset-rhyme matching, showed greater improvements in phonemic perception and articulatory accuracy, than a control group who listened to computerized books [240].

As the largest subgroup of children with language disorders has both phonological and morphosyntactic impairments (35% to 77%), Tyler and colleagues (2003) not only investigated the effect of phonological interventions but they also investigated the use of goal attack strategy in changing morphosyntactic and phonological abilities. They investigated 47 children with language and speech difficulties between 3 years and 5 years 11 months. They found that the greatest change in morphosyntax could be achieved after a 12 week intervention that used an alternation intervention strategy and an intervention where morphosyntactic change was addressed first, compared to a no-treatment control group. The alternation strategy involved both morphosyntactic and phonology interventions. Secondly they presented a morphosyntactic intervention during the first 12 weeks of intervention followed by 12 weeks of phonology intervention. After 24 weeks of intervention the change was greatest for children receiving alternating goal attack strategy compared to the other strategies. No significant differences were found in phonological change between the different strategies after either 12 or 24 weeks of intervention. Compared to the no-treatment group, phonological change was greater in morphosyntax first, alternating and simultaneous strategies.

Segers and Verhoeven (2004) reported a number of studies who proved the effectiveness of computer phonological awareness training for typically developing children and children at-risk for reading problems. They investigated the effectiveness of a short intensive computer phonological awareness training for children with specific speech and language impairment. It is concluded that a computer intervention consisting of tasks training phonological awareness (word awareness, syllabic awareness, rhyme awareness and phonemic awareness) were effective but no additional effect was found for speech manipulation (slowing speech rate and enhancing transitions).The effect size of treatment for this group, compared to the control group, continued to be average 18 weeks after intervention. Probably longer intensive treatment would be necessary to show an effect.

Other factors like direct intervention, additional listening homework or differences in intervention games could have been responsible for the fact that manipulation of speech did not show different effects. This study only used natural speech and this could explain the fact that manipulation of speech undid the positive effects of the intervention [241].

Like the outcome in the studies of Gillon (2000, 2002) [238, 239], Denne and colleagues (2005) proved the effectiveness of phonological awareness training in the more constrained conditions within speech and language therapy clinics. Results were less dramatic then in the former studies. After training, phonological awareness improved significantly, but after 2 months no effect was found on literacy and uncertain results were obtained for the effect on speech. Smaller sample sizes, less equal baselines and individuality in children are a few of the factors that could be responsible for these different outcomes [243].

Due to the fact that awareness of individual phonemes is acquired only in the early school years, the fact that speech and language therapy require awareness of phonemes and that therapy is typically attended for at a pre-school age (pre-literate stage),

Hesketh and colleagues (2007) investigated the possibility of teaching phoneme awareness skills to pre-literate children with speech disorders. They conclude that a skill like isolation of word-initial phonemes can be triggered by therapy in many pre-school children. More demanding tasks like word segmentation and phoneme addition and deletion were only required by a minority of children. This knowledge is of high importance when pre-literate children are given speech and language therapy using phoneme awareness tasks [245].

Some of the children with reading disabilities show greater difficulties using the phonological strategy while other often experience more problems with orthographic word decoding. As there is already strong evidence for the effectiveness of phonological training on reading skills, this does not mean that all children with reading difficulties benefit from that kind of therapy. Gustafson and colleagues (2007) reported that children with pronounced phonological problems benefited more from phonological training than from orthographic training on general word decoding skills.

They suggest that training should focus on the weakness of children with reading problems, rather than on their strengths in word decoding [244].

Conclusion

Phonological interventions, using phoneme deletion, segmentation, proved to be effective for children with expressive language disabilities. Children improved on phonological awareness, speech production, reading accuracy and reading comprehension. As children with spoken language impairments frequently experience persistent written language difficulties and as these difficulties often contribute to poor academic performance and behavioural disorders, more research is necessary demonstrating the long-term benefits from phonological awareness interventions. There is also need for further research focussing on receptive language difficulties. Children with expressive phonological problems are not a homogeneous group (some experiencing problems related to production of speech sounds; others related to phonology) and the inconsistent terminology of speech and language disorders in literature is frustrating and has implications for treatment. The proposition can be made that different approaches to therapy may be required. Some children with good phonological skills may only need therapy to improve articulation while other children with more severe problems in phonology will benefit more from a different approach.

Evidence of lexical interventions

Having read the articles focussing on lexical interventions and after judging them for overlap with the review and HTA report, only one study met the inclusion criteria [246]. The randomized controlled trial of Robertson and Weismer (1999) [219]and the study of Girolametto and colleagues (1997) [215]although included in the review of Law and colleagues (2003), will be briefly mentioned in order to provide some more information concerning lexical interventions [212].

Girolametto and colleagues (1997) proved the effectiveness of repeated presentation of pre selected words following 11 weeks of intervention implemented by the mother (trained in the Hanen-program) of children with expressive vocabulary problems. The intervention appeared to be effective 3 weeks after intervention. Children used a greater variety of complex syllables, used more phonemes and consonants [215].

Robertson and Weismer (1999) investigated the effects of an interactive intervention, stimulating development of vocabulary and the use of combination of words in the social context. Speech therapists (working with a small group of children) verbally described the actions of the children, repeating them (adding certain semantic or grammatical information) in 2 sessions of 75 minutes per week for 12 months. Children in the treatment group significantly improved on vocabulary and combining more words (length of utterances, lexical diversity, total number of words, lexical repertoire) compared to the delayed intervention group [219].

Kouri (2005) examined the effect early lexical intervention with a therapy using auditory bombardment (AB) (children listened to amplified target words in games that specifically evoke production of the targets) followed by play modelling, and a therapy using elicitation (verbal and non-verbal reactions of parents on the play) and imitation prompts. The lexical production of words was measured during the intervention and 2 weeks after the intervention. Children (n=29) between 19 and 36 months, with expressive and/or receptive language delay received during 5-7 weeks, twice weekly 50 minutes of training (for a total of 10 individual sessions). Treatment was provided by student clinicians together with the parents.

Elicitation and prompting proved to be more effective for frequency and quickness of learning target words. The two interventions showed no significant difference in the total percentage of target words 2 weeks after treatment in the generalization session at home [246].

Conclusion

Although vocabulary based interventions proved to be effective in the abovementioned studies, no conclusions about long term outcome and generalizations could be drawn.

Due to the small number of included studies and the differences in intervention methods, implementers of the intervention, used measures, duration and intensity of the intervention… it is very difficult or even impossible to compare the abovementioned studies and make one conclusion about the effectiveness of lexical interventions. More uniform research including follow-up is needed.

Evidence of grammatical interventions

Due to the pervasiveness of delays in grammar and the slow development of grammatical morphology among children with language impairment, the development of language interventions to facilitate grammatical development are worthwhile to discuss. Having read the articles focussing on grammatical interventions and after judging them for overlap with the review and HTA report, only two studies met the inclusion criteria [248]; [247]. Whereas studies mostly involved children with expressive language difficulties and excluded children with receptive language impairments, Bishop and colleagues (2006) focussed on children with receptive language difficulties [248].

ishop and colleagues (2006) evaluated a computerized grammatical training program (based on the FastForWord program that will be addressed later in this review) designed to make comprehension of spoken sentences more fluent, accurate and automatic. A sample of 36 children between 8 and 13 years with persistent receptive language difficulties was drawn. The research compared 2 experimental groups with each other and with an untrained control group. The first experimental group needed to respond to reversible sentences using speech stimuli with pauses before critical phrases. The second group responded to the same, but acoustically modified stimuli. Although responses speeded up as the training progressed and children became familiar with the game (most children performed above change), accuracy remained below 95% correct for constructions like above/below and reversible active/passive. No differences were found between trained and untrained children on language and auditory outcomes.

Bishop and colleagues (2006), like Cohen and colleagues (2005) [263] could not deliver proof of the effectiveness of computerized training using acoustic modified stimuli to improve grammatical skills and comprehension. Further research is needed in this area [248].

Given the special difficulties that the grammatical rules for tense and agreement morphemes pose for children with speech and language impairments, there have been efforts to facilitate these children's use of such morphemes. Target morphemes differed from study to study. Even when studies reported gains in use of certain morphemes, they did not result in acquiring complete mastery of the targets after treatment.

As many children with speech and language impairments are limited in their use of grammatical morphemes pertaining to tense and agreement, an intervention was done by Leonard and colleagues.

Leonard and colleagues (2006) performed an extension to study [247]. In the earlier performed study the treatment consisted of 48 individual sessions over 12 weeks for 3 to 4 years old children with specific language disorders. The first intervention focussed on the use of target stimuli while the interventionist was reading a story and the second intervention used 'recast' of the conversation during play with the child. The gains they found in the use of target forms could be attributed to the intervention. Indirect benefits occurred if the no target morphemes shared multiple features with the target morpheme. In Leonard and colleagues (2006) similar results were found after a longer time of treatment (96 interventions) as children showed significantly larger gains on the trained target than on the controls (-ed) who were not included in the intervention.

Possible treatment-related generalization across morpheme types occurred but there was also evidence that one morpheme type influenced another when none of them were the target of intervention [247].

Conclusion

Although the study of Bishop and colleagues (2006) [248] did not show significant improvements, it was included in the review because the used intervention program Fast ForWord will be discussed further in the study of Cohen et al. (2005).

In spite of the evidence for treatment effects of the intervention of Leonard and colleagues (2006)[247], there must be acknowledged that the acquisition of tense and agreement morphemes could have been influenced by the fact that the participants of the study were very young and the effect of the intervention can be attributed to maturation processes. Much more language intervention research is needed before a realistic conclusion can be drawn about the effectiveness of intervention facilitation grammatical abilities in children with language impairments.

General conclusion speech and language disorders

Although a relatively large volume of studies about the effectiveness of interventions for children with speech and language impairments exist, only a few studies met the predefined selection criteria. Randomized controlled trials provide the strongest evidence of the efficacy of interventions, but are not easy to implement. In psychosocial treatments the researchers and parents are aware of the intervention condition the child is in. Ethical difficulties in random assigning children to either the control condition or the treatment condition are a problem in this area of research.

In addition, it is very difficult to compare the studies, due to differences in severity of speech and language impairments, duration and severity of treatment, providers of treatment, age of participants, used measures… No conclusion can be drawn about 'the' most effective method to treat children with speech and language impairments. In this part of the review the only general conclusions that can be drawn concerns the effectiveness of speech and language interventions on children with expressive phonological or expressive vocabulary difficulties, mixed findings in syntax interventions and no to little effects for treatment of children with receptive language difficulties. In general, there seem no differences between the use of trained parents and clinicians as the administrators of the interventions but some studies suggested that parent-based interventions are more effective.

No differences between individual and group therapy were reported. Some evidence was found concerning phonological awareness training and computer phonological training. Some of these studies report long term effects whereas in other studies the effects fade away after a couple of months. Some evidence was found for lexical interactive intervention and an intervention of elicitation and prompting of words by both clinicians and parents.

As studies varied in intensity, duration and had no follow-up, more research in this area is needed. Evidence for grammatical interventions was mixed and only one study reported treatment effects after a long, intensive intervention period.

By searching the different databases, no articles were found concerning the effects and differences between mono- and multidisciplinary treatment. In the included studies, treatment interventions were mainly done by a researcher. Therefore, no conclusions could be formulated about the evidence of the kind and the number of disciplines needed to be incorporated to deliver evidence-based psychosocial treatments.

It is also remarkable that no statements could be made about the effectiveness of treatment in comorbid disorders. The included studies only investigated psychosocial treatments within children with the only diagnosis 'speech and language disorders'. The co-existence of other comorbid disorders was not mentioned in the description of the subjects in the included studies. This is noticeable because comorbid disorders are widespread. More research is needed concerning these topics. The mean age of the participants in the included studies is about 5 to 6 years; therefore conclusions about the effectiveness of these psychosocial treatments could only be generalized for this age group.

In general it can be concluded that more in depth research is needed. Future studies about the effectiveness of interventions for children with speech and language difficulties should use larger sample sizes, widely recognized standardized tools and include a long-term follow up. Until now, no recent clinical guidelines (2003-2008) for the treatment of children with speech and language disorders were found (after search in the National Guideline Clearinghouse and the Tripdatabase).

3.4.3 Learning disorders

3.4.3.1 Introduction

No reviews or meta-analysis concerning learning disorders were found to be of good quality and therefore they were not included in this review [222;223;205, 210, 226-228, 231, 232, 264]. Mostly the studies did not meet criteria of adequate search strategies, were published before 1997, included single-subjects… As overlap occurred with some studies previously discussed, some articles concerning learning disorders were discussed earlier in this review and will only be briefly mentioned. Further chapters are divided by main focus of the intervention but overlap exists between interventions or interventions using aspects from other interventions. Interventions included in this review focus on visual attention, acoustic modified stimuli, auditory discrimination, hemispherical stimulation, metacognitive strategies, explicit alphabetic code and training of phonologic decoding, metaphonological interventions, alphabetical principle (teaching the alphabetic code; words divided in phonological units/ presenting word combinations, morphological interventions, interventions based on word repetition and interventions teaching strategies for reading whole texts and word comprehension.

3.4.3.2 Reading disorders

Evidence-based interventions for reading disorders

Evidence of interventions based on visual attention

Having read the articles focussing on visual attention and after judging them on the predefined quality criteria, 2 studies were found meeting the inclusion criteria [265;266]).

This intervention is based on the theory of visual perceptual deficits (a defect in processing visual information). In this theory the concept of attention relates to oculomotor readiness in reading and attention for the target location is made before a saccade can be made to that location. Attention drives that saccade.

Solan and colleagues (2003) assume that in reading, retinal images (text) are sampled twice in the visual system, once by the magnocellular system (M-cell, parafoveal), then by the foveal, parvocellular pathways, suggesting that saccadic and perceptual tasks are performed concurrently in typical readers. In individuals with reading disabilities, the temporal synchronisation between M-cell and P-cell pathways passes without fine-tuning.

Solan and colleagues (2003) used computer based attention therapy to improve visual attention and effect reading comprehension. They trained perceptual accuracy, visual efficacy, visual search, visual scan and visual span and found significant improvements in attention and reading comprehension scores after attention therapy. Whereas the control group did not improve on reading comprehension and on attention, the experimental group significantly did [265].

Whereas the abovementioned authors, propose the mangnocellular system as the neural basis for the visual perceptual deficits in dyslexic children, Facoetti and colleagues (2003) [266] believed that reading disabled children experience problems in the ability to control the visual spatial region of unattended information or to inhibit information in unattended location outside the attentional focus. Selection of relevant information is important in reading and some evidence is found that dyslexic children experience impairment in orienting of attention and attentional focussing. Therefore Facoetti and colleagues (2003) studied the efficacy of two different rehabilitation procedures. The VHSS (visual hemispheric stimulation) interventions trained children with reading disorder to perform fast endogenous attention orientating, by presenting briefly flashed words in the peripheral visual field. The children needed to detect a symbol after being primed with either a correct, incorrect or neutral cue. Children in the speech treatment program received a treatment based on various intervention programs. The VHSS training led to a significant improvement in reading speed and accuracy. The children receiving the VHSS training showed significant changes in their attention inhibition process and the training proved to be more effective than the traditional speech training in this short time interval [266]. The knowledge that there are different aetiologies for reading disorders, lead to different kind of interventions.

Abovementioned studies demonstrated both effective visual attention intervention methods, starting from a different kind of view concerning aetiology and therefore can not be compared with each other. More uniform and long term research is needed concerning the effectiveness of interventions focusing on visual attention training.

Evidence of interventions based on acoustic modified stimuli

Articles focussing on the use of acoustic modified stimuli in intervention for reading disabled children are multitudinous, but after screening on predefined quality criteria, only 2 studies were withhold (Cohen et al., 2005;[267].

The assumption that children with learning / language difficulties often experience problems with the temporal processing of auditory/visual information (poor auditory resolution, problems with distinguishing sounds that are brief or occur in rapid succession) led to a certain number of intervention programs that use acoustically modified stimuli. These stimuli are presented longer (50%) and louder (20dB) than normal spoken language. The Fast Forword is a computerized intervention based on the principle of acoustic modified stimuli (Tallal, 2000 in [267]. It involves a set of 'games' that train different aspects of language (auditory discrimination, phonological awareness, sentence comprehension). Interventions took about 2000 to 3000 minutes, in sessions of 100 minutes per day, for 4 to 5 weeks. The program starts with maximum modifications of intensity/duration and lessens until the presented stimuli resemble the normal language. Several studies have been published, evaluating Fast ForWord by using randomized controlled trial designs but most of them were not found in our literature search or were excluded from the review.

Cohen and colleagues (2005) divided 77 children between 6 and 10 with severe receptive-expressive language impairments in 3 groups. The first group received intervention with the Fast Forword program (FFW) at home for 6 weeks. A second group used commercialised and computerized language activities (presented like computer games) and the control group did not receive any treatment.

Each group made significant improvements on standardized language outcome measures but Cohen and colleagues (2005) did not found an additional effect of FFW intervention (Cohen et al., 2005). Bishop and colleagues (2005) evaluated a computerized program based on FFW in an intervention with receptive language impairments but could not prove the efficacy of the intervention with modified speech compared to an intervention with ordinary speech.

Children could be trained to spell new words in the context of the computerized game, but the training did not generalize to improvements in phonological awareness (they did not better than the control group for spelling test with different words or nonword reading) [267].

Whereas in multiple studies a link between learning disorders/ speech and language disorders and temporal auditory as well as visual information is made, this theory is still the subject of scientific discussion. The abovementioned studies could not provide evidence for a computer based intervention and the idea that acoustically modified speech input enhanced comprehension in children with language/ learning disorders (Cohen et al., 2005 and [267].

Possibly the assumption that all children with a reading disorder have problems with temporal processing is wrong and research should investigate the possibility that only a subgroup (children with temporal processing difficulties) will benefit from programs like FFW.

Evidence of interventions based on discrimination of sounds

The following interventions use spoken language and are based upon the assumption that reading disorders are the result of a specific problem with auditory (speech) discrimination of sounds. Children with a reading disorder show less well-defined phoneme representations than normal readers. The intervention used by Gonzalez, Espinel and Rosquete (2002) [268]examined the influence of speech perception as one of the components of phonological training on phonological and reading abilities of children with reading disorders. In their study they presented tasks that require recognition and classification of phonemes.

The combination of auditory discrimination training and a metaphonological intervention is more effective than the metaphonological intervention alone. They found also an effect of the interventions on the actual reading.

Evidence of hemispheric-based linguistic strategies

This type of treatment is based upon the theory of Bakker (in [269]. His model says that in the early stages of normal reading acquisition, children employ predominantly right-hemisphere-based visuospatial strategies. As children mature, their reading strategies shift to left-hemispheric-based linguistic strategies (automatisation). A lack of balance between the two hemispheres results in a reading disorder. The lack of maturation (the child keeps using the right hemisphere) shows in correct but slow and difficult reading (P-type) and children using the left hemisphere show fast reading, but guessing and with a lot of mistakes (L-type). Some children make both mistakes (M-type). Bakker (in [269] proposed specific interventions for each type of reading disorder based upon hemispheric stimulation. In the hemisphere-specific stimulation (HSS) words are presented either to the right or left visual field, or to the right or left hand (contra lateral to the hemisphere that is less often used). In the hemisphere-alluding stimulation (HAS) perceptually complex text is presented to L-types to stimulate right hemisphere, while rhyming exercises and filling in missing words are used to stimulate the right hemisphere in P-types.

While Bakker proved the effectiveness of the HSS and the HAS training for reading fluency in P-type dyslexics and greater reading accuracy in L-type dyslexics, [269] also investigated the effect of intervention of hemisphere stimulation. Children with dyslexia were given a treatment program that was either designed for their particular type of dyslexia (P-type or L-type) or an intervention inconsistent with their type of dyslexia. All participants made gains on their reading measures, regardless of the type of treatment given.

Contrasting results were found concerning interventions based on hemisphere-specific stimulation. More in depth and long term research is needed.

Evidence of interventions based on metacognitive strategies

These interventions are based on the principle of analogy, for example the PASS Remedial Program (PREP), a word reading program which focuses on 4 major cognitive processes (planning, attention, simultaneous, and successive processing). Our literature search did not provide us with studies of good quality concerning metacognitive strategies.

Evidence of interventions based on the alphabetic code and training of phonological recoding

The common basic assumption for treatments based on the psycholinguistic model is in contrast with the acquirement of spoken language and states that learning to read is culturally defined and need explicit and systematic teaching. In our alphabetic system, the written code represents the spoken words on the level of phonemes.

This is why poor phonological awareness and specifically the ability to manipulate the phonemic segments of spoken words can hinder successful reading. This knowledge provides the theoretical motivation for promoting phoneme awareness and letter knowledge (two key foundations of the alphabetic principle) in reading intervention programs. Only two studies using the alphabetic code met the predefined quality criteria and were included in this chapter [270, 271].

Hatcher and colleagues (2006) evaluated the effectiveness of a small group reading intervention based upon letter identification, phoneme awareness/linkage exercises, writing and reading books. The results of this study were encouraging and showed that after only 10 weeks of intervention, the children in the intervention group made gains of 4 standard score point on a test of single word reading ability compared to the 'waiting list' control group. The program used alternated small group (N=3) interventions and individual teaching.

In the subsequent 10 weeks both groups received the intervention and whereas the control group caught up with the intervention group, the latter slowed down. These results have important educational implications, as these kinds of interventions are realistic to be delivered by teaching assistants [270].

As most research indicates that phonologically-based interventions and whole-word methods both are effective ways to improve word recognition skills in children with reading disabilities, the study of O'Shaughnessy and Swanson (2000) aimed at increasing phonological awareness through two kinds of treatments. The first treatment consisted of direct instruction of oral language activities and focused on the level of phonemes. The second treatment consisted of contextualized written language activities and focused on the level of onsets and rimes. Children in both treatments made significant gains in beginning reading skills, learning the specific skills taught in their programs, and applying those skills to uninstructed material, compared to children in a control group. The conclusion can be drawn that phonological awareness can be developed both directly through systematic oral language activities and indirectly through written language activities. Although the duration of intervention was too brief to determine differences between the two reading interventions, this effective systematic reading intervention delivered in small group, in a public school setting require more research[271]

A better model for future research would be one where classroom teachers are trained in empirically validated reading interventions instead of the researchers themselves.

Evidence of metaphonological interventions

Metaphonological interventions are often investigated but the literature search revealed only a limited amount of approved studies ([268, 272, 273]) Metaphonological interventions focus on the competence to analyse spoken words explicitly in phonological units. The beginning reader needs to be aware of the fact that words can be analysed in phonemes and that these phonemes can be presented in writing in letters or groups of letters.

Teaching phonological awareness and teaching the phoneme-grapheme link is necessary in learning to read or spell.

Although the meta-analysis of Ehri and colleagues (2001) did not meet the quality criteria it is briefly discussed in this review. They analyzed studies of training in phonological awareness in normal reading children and children with reading problems/disorders. No great differences were found between individual interventions or interventions in small groups.

Most effect was reached when both analysis (children need to analyse the spoken words in their phonemes and pronounce every phoneme slowly) and synthesis (the consecutive phonemes are blend to form one word) were trained. To be effective the interventions also need to include explicit training in phoneme-grapheme linking. The use of tactile material (plastic letters) also seems to be very effective [223].

Gonzalez and colleagues (2002) questioned the effectiveness of metaphonological interventions, containing a training of speech discrimination compared with an intervention without the discrimination training.

Both interventions emphasized the acquisition of individual letter-sound correspondences and phonological awareness skills (phoneme identification, segmentation, phoneme deletion, phoneme blending) but one group received this intervention together with a training of speech discrimination (phoneme discrimination in syllables, word pair categorization and phoneme discrimination in words), while the second experimental group received the same trainings but without the speech perception component. Both interventions show similar positive effects on metaphonological skills (phonological awareness) but only the intervention that trained both speech perception and phonological awareness (with visual support) was effective in improving reading compared to the control [268, 272, 273].

Lovett and colleagues (2000) proved the effect of a combination of methaphonological intervention and an intervention that teaches strategies for reading words. That combination proved to be more effective than an intervention that only taught one component of the interventions (see further)[268, 272, 273]

Vaughn and colleagues (2003) investigated the effectiveness of an intervention that focussed on fluent reading, phonological awareness, instructional-level reading, word study and progress monitoring taught as an individual/small group/group of 10 students[273]. Just like Ehri and colleagues (2001) [223] proved that metaphonological small group interventions are as effective as individual interventions, Vaughn and colleagues (2003) confirmed that an individual metaphonological intervention or an intervention in small groups is more effective than that intervention for a group of 10 students.[268, 272, 273]

The abovementioned studies provide some evidence that the combination of metaphonological interventions with either speech discrimination intervention or with an intervention teaching strategies for reading words proved to be effective. An intervention in small groups or individual training was more effective than an intervention in a group of 10 students. Although the described studies resemble in type of intervention, one definite conclusion can not be drawn due to different sample sizes, different measures, differences in severity of the reading problem…

Evidence of interventions based on the alphabetical principle

The alphabet principle is based on the idea of making the relation between spoken sounds and written symbols more explicit. Interventions based upon the alphabetic principle use different and special techniques to explain letter-sound associations. The literature search provides us with 3 studies that met the pre-defined quality criteria [274,275].

Berninger and colleagues (1999) followed the connectionist approach (not based on phonic rules) where the learner computes connections of varying strengths between the spelling (orthography) of written words and the phonology (sounds) of words already represented in memory (learning the code through induction) [274]. The authors compared three interventions concerning three different levels of correspondence between sounds and letters (whole words, subwords (level of letter/sound)

and a combination of both) in children with a mean age of 7 years and 5 months. They selected words with three levels of complexity and correspondence (regular and predictable, irregular but predictable, irregular and unpredictable).These words were presented with a rising level of difficulty. Standardized tests showed positive results for all three interventions for the reading of taught words and pseudo-words. The groups receiving explicit letter-sound correspondence intervention, scored best for the post-test on reading. These findings suggest that this intervention is most effective in generalisation of non-trained words.

An increasing number of studies implement computers in reading interventions. The possibility to coordinate speech with written word presentation, make these kinds of interventions very attractive for researchers.

A computer can orthographically segment an 'speak' the word at (sub) syllable levels and can highlight that segment and presentation when corresponding with speech sound (strengthening the relation between groups of letters and their sounds).

Jiménez and colleagues (2007) investigated four reading training conditions (whole-word, phoneme, syllable and onset-rhyme). They indicate that children with reading disabilities, who participated in computer based phoneme or syllable training, improved their phonological decoding skills (word and pseudo-word reading).The onset-rime condition and the whole-word condition did not contribute to improve phonological decoding skills. Children asked for more speech feedback under conditions that required extensive phonological computation (low frequency words and long words). Reading time was longer for long words in the phoneme group. In this study, participants were able to ask for the spoken form of the word, reading on the computer with speech feedback, improved the phonological decoding skills, especially when the instruction was phonemic and syllabic based [275].

A careful conclusion can be made that explicit letter-sound correspondence intervention and a computer based phoneme or syllable training showed to be more effective than interventions based on presenting whole words. Both studies are not comparable, mainly because the first one deals with English speaking children and the latter with Spanish speaking participants. This knowledge influences to what extend conclusions can be made about both interventions.

Evidence of interventions based on the alphabetical principle/ words divided in linguistic units

As the following interventions, accepted in this review consist of interventions offering words divided in linguistic units (for example in syllables, begin-clusters or phonemes) some of them show overlap with the abovementioned studies [220;274;276; 277; 278].

Torgesen and colleagues (1999) compared two programs varying in the intensity of instruction in phonemic decoding with each other (the embedded phonics condition (EP) and the phonological awareness plus synthetic phonics condition (PASP)), with a control group and with a group receiving a regular classroom reading program (RCS). The EP intervention consisted of four main activities, namely: a) recognizing small groups of whole words by using word level drill and games, b) letter-sound correspondences, c) building sentences, and d) reading the written sentences. The PASP intervention consisted of explicit instruction in phonemic awareness. They lead children to discover and label articulatory gestures that are associated with each phoneme. Children were provided with 88 hours of one-to-one instruction beginning the second semester of kindergarten and extending through second grade. The PASP group had significantly stronger skills than the EP group in phonological awareness, phonemic decoding and untimed context-free word reading. They were also stronger on word-level reading skills than children in the RCS and the no treatment control group. Although the most important outcome for reading instruction should be situated in comprehending written text, no reliable differences were found between the groups for reading comprehension. Only when very explicit and intensive instruction in phonemic awareness and phonemic decoding skills is provided, children can improve their word-level reading skills [220].

Berninger and colleagues (1999) proved in their study already the effect of an intervention that focuses on presenting words divided in linguistic units above the presentation of whole words (see earlier) [274].

Greaney and colleagues (1997) [276] suggest just like Berninger and colleagues (1999) that offering words in linguistic units are more effective than offering whole words [274]. Children of 8, 2 years old, with a reading disorder received either a training involving the use of rhyme spelling units or a training that focused on item-specific learning and sentence-level strategies.

The program also included instruction in metacognitive knowledge about how and when to utilise rhyme analogies as decoding strategy. Children trained in using the rhyme spelling units scored better on both the post-test as the 1 year follow-up than peers who received the intervention with whole words. An immediate post-test and delayed post-test showed higher scores for the rhyme analogy training on the reading of isolated words, pseudo-words, for reading words with common rhyme units and the identification of rhyme units. No difference was found for reading words in context.

Children that were trained in using rhyme did not differ significantly from younger normal reading children in a control group (matched on reading age at the beginning of the study). Children trained with the whole words significantly differed from that control group for all tasks, except the segmentation in phonemes. The concluded that phonological skills teaching combined with metacognitive strategy training constituted an effective reading intervention strategy for poor readers. Systematic strategy training using rhyme spelling units resulted in generalized achievement gains and transfer to uninstructed words. It proved to be more effective than a training involving item-specific learning (whole words) and sentence-level strategies. The post treatment performance of the rhyme analogy training remained the same over a 1 year period.

Struggling readers experience problems in syllabicating words to read them. Bhattacharya and Ehri (2004) conducted a study to see whether students with poor word-reading skills benefit more from syllable treatment (practice in breaking words into syllables and matching the spelling of syllables to their pronunciation) than from whole-word treatment [277]. Graphosyllabic instruction helped decoding novel words, memory of how to read words and remember the spelling of words compared to no treatment. Whole-word treatment did not prove to be effective on transfer tasks compared to controls.

The results also showed that the effect were more prominent for adolescents reading at a third-grade-equivalent level than for adolescents reading at a fourth- and fifth-grade-equivalent level.

It is well-known that text-to-text speech conversion can facilitate reading comprehension in students with reading disabilities. Children with LD experience problems in phonological processing which can negatively influence their reading comprehension. The knowledge that they have difficulties in decoding print, but experience no difficulties in understanding spoken language, supports the idea of using optical character recognition systems. These systems convert printed text to spoken language and can facilitate reading comprehension in children with reading disabilities. Due to the broad base of research on explicit instruction in phonological awareness, automaticity and fluency, Higgins and Raskind (2004) were driven to find the most effective reading program to improve reading and spelling. They found that a computer speech Recognition-based Program (SRBP; bimodal presentation of text, practice in analysis and discrimination of similar sounding and looking at words, and interest-driven, self-paced materials) and a computer and text-based Automaticity Program (AP; systematic explicit instruction in phonological awareness and phonetic decoding skills) showed significant differences over a control group in improving word recognition and reading comprehension. None of the intervention groups proved significant differences in spelling over the control group. The SRBP also improved on phonological elision and non word reading efficiency tasks compared to the control group and the AP showed significant differences for process and reading efficiency measures [278].

In general the conclusion can be made that intervention using the presentation of words divided in linguistic units are preferred above interventions with whole-word presentations. As none of the abovementioned studies are completely comparable, no real conclusion about effectiveness can be drawn, nor can one recommend one of them as the best one.

Evidence of interventions based on the combination of making the alphabetical code explicit and presenting words

In addition to the abovementioned studies, 4 articles were approved and included in the next chapter [272, 279-281]

Torgesen and colleagues (2001) compared two interventions, both of which were phonemically explicit and systematic but varied in their method and in depth and extent of phonemic decoding practice. Children received one-to-one instruction in a summer reading clinic outside of school, two 50-minute sessions per day for 8-9 weeks. One group received the Auditory Discrimination in Depth Program (ADD) (more recently:

Lindamood Phoneme Sequencing Program for Reading, Spelling and Speech, Lindamood & Lindamood, 1998)) that focuses on stimulating phonemic awareness via articulatory cues (learning to 'feel' and 'hear' the individual sounds in words) and building phonemic/articulatory awareness and individual word-reading skills. The second group received the Embedded Phonemics program (EP) that stimulates phonemic awareness through writing and spelling activities, teaches phonemic decoding strategies directly and spends much time on reading and writing connected text. Both approaches included explicit instruction in word reading skills, but the EP intervention involved less time in decontextualized phonics instruction and more time for reading connected text. Both groups gained in age-adjusted standard scores on measures of decoding and comprehension and maintained their gains 2 years after finishing the intervention, although many of them remained slow readers. The ADD condition showed stronger effects in accuracy of phonemic decoding skills during intervention, significantly greater growth in accuracy and fluency of word reading in text during intervention but these findings were not maintained after follow-up [281].

Early reading instruction plays a critical role in the prevention of reading difficulties. When children do not learn to read adequately in the primary grades, there is a higher risk of persistent reading difficulties throughout their school years.

Torgesen and colleagues (2001) provided already an indication of the effectiveness of a tertiary intervention for students with severe reading disabilities in Grades 3 through 5 (see earlier) on decoding skills and comprehension, but failed to effectively improve word fluency [281]. Denton and colleagues (2006) (Denton, Fletcher, Anthony, & Francis, 2006) investigated the effectiveness of a tertiary reading intervention for students with persistent reading difficulties, who did not respond to primary-and secondary-level intervention provided in Grade 1. The purpose of this study was to evaluate the effectiveness of two interventions: an 8-week program of explicit decoding-instruction (similar to the one Torgesen and colleagues (2001) used) and an 8-week program of oral reading fluency instruction. The explicit decoding-instruction (Phono-Graphix) resulted in significant growth in decoding, fluency and reading comprehension, whereas the reading fluency-instruction positively influenced reading accurately and fluency in list of words and connected text. Students that received already Trier 1 and Trier 2 interventions, but remained impaired, had a stronger response to this intervention than the control group [281].

Although long term effects of 2 year were found in the study of Torgesen and colleagues (2001), no other follow-up research was included and therefore no conclusions can be drawn about the long lasting effects of these interventions [281].

Lovett and colleagues (2000) studied a combination of metaphonological intervention and a metacognitive intervention that teaches strategies for reading words. That combination proved to be more effective than an intervention that only taught one component of the interventions. The metaphonological intervention, Phonological analysis and Blending / Direct Instruction (PHAB/DI) trained sound analysis and blending skills by teaching the child to pronounce each sound in words slowly, one at a time and

in a left-to-right sequence. The training requires that the child hears the individual sounds in a word, develops an awareness of the subsyllabic unit within the spoken words and combines speech sounds to form words. Afterwards the words are presented in printed form. The Word Identification Strategy Training (WIST) consists of 4 strategies involving: (a) word identification by analogy, (b) seeking the part of the word that you know, (c) attempting variable vowel pronunciations, and (d) 'peeling off' prefixes and suffixes. The WIST program includes a system of metacognitive mnemonics (monitoring to see if a particular strategy is working, if problems occur switch to another strategy, flexibility in looking at alternatives, persistence until an good answer is achieved) to help children to acquire general routines for effective strategy application and evaluation.

Both the letter-sound approach of PHAB/DI and the letter-cluster-sound approach of the WIST made improvements in word identification accuracy and decoding skills possible for severely reading disabled children [272].

A phonologically based reading program (Spell Read) implemented in the study of Rashotte and colleagues (2001), starts form the assumption that reading is preliminary and auditory process and that mastering the sound system of language and dispose of strong phonological and auditory skills are key elements in learning to read and spell efficiently. The program integrates elements of instruction in phonemic awareness, phonics, reading and writing for meaning and was delivered in small groups (3-5) over 8 weeks. It proved to have a significant impact on phonetic and word-level reading skills and reading comprehension skills of deficient readers in first trough sixth grade. The only reading skill that did not show significant growth when compared to the control group was reading fluency. Reading fluency appears to be one of the more difficult reading skills requiring a large vocabulary of words and therefore the conclusion can be drawn that the intervention of 8 weeks was too short to show some effect on fluency measures [280].

Evidence of interventions based on morphology

The literature search did not reveal studies about morphological interventions complying with the inclusion and/or quality criteria. The earlier discussed study of Lovett and colleagues (2000) contained a morphological component in their intervention. They suggested that teaching morphological analytic competence can be effective in learning to read and spell, especially in older readers (adolescents) [272].

Evidence of interventions based on repetition of words

The ultimate goal of reading is comprehension, and this requires the complex integration of a multitude of component skills (decoding words, reading fluently and later on an integration of that information contained in words, sentences, paragraphs). As comprehension failures are often linked to difficulties in lower-order skills of reading fluency and/or the higher order skill of text comprehension strategy usage, Therrien and colleagues (2006) conducted a study to test the efficacy of a combined repeated reading and question generation intervention on the reading achievement of students with LD or students at risk for reading failure. The repeated reading program consists of rereading a short and meaningful text until a certain fluency level is reached and should improve reading fluency. The positive outcome on reading comprehension is less proven. The question generation intervention consists of letting readers generate questions during reading. As both interventions showed positive but no conclusive results. Therrien and colleagues (2006) used the 'reread-adapt and answer-comprehend intervention (RAAC). Students receiving the intervention significantly improved their reading speed and ability to answer inferential comprehension questions on the reread passages. They also performed significant better in oral reading fluency (which is a good predictor of comprehension) on independent passages, compared to a control group. Results also indicated the potential of the intervention to improve students' overall reading achievement [282]. But drawing conclusions on the basis of this one study would be dangerous and wrong. Further research would benefit from longer duration of treatment with more students, the inclusion of a follow-up, containing more severely impaired students…

Evidence of interventions based on strategies for reading of text and comprehension of text

These interventions are based on structured presentation of texts and teaching strategies for text comprehension.

Calhoon (2005) examined the viability of peer tutoring as an instructional delivery model for teaching reading skills to students with reading disorders [111]. As in the previous research by Lovett and colleagues (2000) [272] results proved the significant greater gains students made for reading comprehension after peer-mediated intervention

(LST/PALS: peer mediated Linguistic skills Training / Peer Assisted Learning Strategies) and on Letter-word Identification and Word attack compared to students who received traditional whole-class intervention (using a widely implemented remedial reading program).

More specific consisted the LST of systematically and explicit teaching of phonological skills, through letter-sound correspondence, direct teaching of phonetics, phonology, morphology and English orthography. The intervention started with a scripted teacher-led lesson, followed by teacher-directed practice and then practice in peer tutoring pairs. The PALS consisted of partner reading (reading accuracy and rate), paragraph shrinking (to develop comprehension through summarization) and prediction relay (larger texts and (dis)confirming predictions). For the latter intervention the tutoring roles were reciprocal. Although the effectiveness of this intervention was proven by Calhoon (2005) [111], further research should increase the sample size, use random assignments of students to conditions, control for age and IQ

Evidence of interventions based on self-regulating strategies

Two articles that studied the effect of self-regulating strategies on reading in reading disabled children met our quality criteria and were included in the review ([283, 284].

As previous research indicated that knowledge and use of story structure helps readers analyze, organize and remember story content, Johnson and colleagues (1997) studied the use of story structure to analyze and remember story content in 47 students with learning disabilities using a self-regulated strategy development (SRD) model. Four conditions (strategy instruction, strategy instruction plus goal setting, strategy instruction plus self-instruction and strategy instruction plus goal setting and self-instruction) were compared.

The reading strategy resulted in meaningful, lasting and generalizable effects on story comprehension skills. The comprehension of students with learning disabilities was after instruction not different than that of normal achieving students. The explicit instruction in goal setting and self-instruction did not improve the comprehension performance. Additional research is needed to replicate the findings of this study [283].

As students with learning difficulties often fail in processing information in a goal-directed way, in adopting adequate strategies to accomplish goals and in monitoring that strategic process towards achieving goals, self-regulation procedures should help them remediate these failures. Children with learning disorders often are characterized by an attributional style 'learned helplessness' (the believe that their failures are due to their own low abilities and their gains are just because of other causes). [284]compared a self-instructional training to a self-instructional training with attributional training and a no-treatment control group. They found self-regulating procedures to be effective to increase students' reading comprehension strategies. Additional attribution retraining however did not have any effect on student's reading comprehension or used metacognitive strategies.

Implementers of intervention

Of the included studies in this review most of them use experimenters or trained teachers as implementers of the interventions under investigation. Few of them included trained parents or used them in addition to the experimenter or teachers ([237,246, 285].

Although Law and colleagues (2003) [212]proved no differences in effect between the use of professionals or parents as implementers of intervention, the following studies provide some extra information [286]; [246, 285].

Next to the evaluation of the Howard Street tutoring model (Morris, Shaw, & Perney, 1990), Brown and colleagues (2005) evaluated the effectiveness of supervised volunteer paraprofessionals (teacher aides) in delivering that tutorial. The Howard Street Tutoring Program was created to improve reading and reading comprehension skills in low-ability readers. The program aims at improving the word recognition, reading passages, and spelling scores of its participants. Results showed that the tutored group (guided reading in levelled texts with controlled vocabulary, word study and reading for fluency) outperformed the control group

(small- group context guided reading and phonics work) on each of the post-treatment measures and that in the structured tutoring context; the paraprofessional tutors were almost as effective as certified teachers [286].

Lamminmaki et al. (1997) compared two treatment methods for children with learning disabilities. The first treatment focuses on training of specific areas of cognitive skills. This 2 hour training involved orientation in time and space, language/verbal skills, expressive skills and emotional growth, perceptual skills, numerical skills, application and integration of practice skills. This treatment was performed by professionals. Parents were offered the possibility to attend a parents' group for 1 hour per week. The second treatment consisted of games, homework assistance, reading exercises and different kinds of group activities (role playing, motor exercises) and was performed by non-professional trained adults (HAS). Both groups improved on most of the outcome measures. Both groups improved significantly for school achievement. The first group showed the best results in parent's rating of home behaviour. Although both groups improved for reading, the HAS group showed more improvement in reading. Due to the fact that the experiment consisted of two different interventions no real conclusions can be drawn about the superiority of parental implementation of intervention over implementation of an intervention by professionals [285].

Research focussing specifically on the effect of parents or non-professionals on the outcome of interventions for learning disabled children, is needed. Due to the lower costs accompanying these methods of implementation, this should be a reason for more research in this area. The same intervention provided by different implementers over a long time of treatment, could be a good start for further research.

Other kinds of intervention

Some studies that met the predefined quality criteria could not be categorized in the earlier discussed chapters and are clustered in the following chapter [287];[288];[289];[290]; [291, 292].

Higgins and Raskind (2005) investigated the effectiveness of the Quicktionary Reading Pen II (a portable device with miniaturized optical character recognition and speech synthesis capabilities) on 30 students (10-18 years) with reading disabilities. Participants using the Reading Pen performed significantly better on a reading comprehension test than participants without using the Reading Pen [287].

Graham and colleagues (2007) [288]describe the usefulness of the QuickSmart program, a responsive small group intervention that aims to develop word recognition, vocabulary knowledge, fluent reading and use of comprehension strategies. It is designed for persistent low-achieving students in the middle years of schooling and focuses on improvement of the automaticity of basic skills in order to improve higher-order processes (problem solving and comprehension). The program consists of three structured, teacher- or teacher aide-directed, 30 minutes, small group sessions a week for 26 weeks. The program follows a sequence of learning activities that included automatic word recognition, repeated reading of texts, practice of memory and retrieval strategies, timed independent practice activities. A first group of 42 students with LD participated in the QuickSmart reading program and the other group of 42 students with LD participated in the QuickSmart mathematic program.

Compared to 10 high-achieving students and 10 average-achieving students, the results showed that for the intervention group the standardized scores for reading comprehension and mathematics remained below the sores of the comparison groups but they improved significantly from pretest to posttest. The standardized scores of the comparison groups did not differ significantly between pretest and posttest. When looking at response rate and accuracy, QuickSmart students were able to narrow the gap between their performances and that of the comparison groups.

Chenault, Thomson, Abbott and Berninger (2006) investigated the effect of prior delivered individual attention training on a latter provided group composition instruction. Students with dyslexia, receiving initially the 'Pay Attention!' training made significant more progress in composition once composition instruction was taught, then those receiving reading fluency training prior to the composition training. The 'Pay Attention!' training alone was not sufficient.

The results of this study are important because they provide information concerning the suggestion that instructional components should be sequenced within lessons and over time, in a certain way [289].

Bouldoukian and colleagues (2002) investigated the effect of individually prescribed coloured overlays on the rate of reading. The researchers selected 29 children (mean age 11 years and 4 months) and 4 adults (18, 19, 30 and 40 years) who consulted a specific learning difficulties clinic, received treatment to normalise any conventional optometric and orthoptic anomalies, and reported symptomatic relief from coloured filters [290]. These subjects needed to carry out the Wilkins Rate of Reading Test under two conditions, one with the filters and one using a control filter. They concluded that reading performance can improve by using individually prescribed coloured overlays (controlled for optometric factors and placebo effects).

Manset-Williamson and Nelson (2005) compared the use of two supplemental balanced and strategic reading interventions targeting decoding, fluency and reading comprehension of students with a mean age of 11 years and 6 months. The two approaches only differed on the degree of explicitly of the comprehension strategy instruction. Both groups made progress in decoding, fluency and comprehension. The PDF/EC (Phonemic awareness/analysis, decoding, fluency instruction + Explicit comprehension) condition made significantly greater gains in the immediate measure of reading than those in the PDF/GR (Phonemic awareness/analysis, decoding, fluency instruction + guided reading) condition. The more explicit comprehension strategy instruction was more effective than the less explicit treatment [291].

The study of Nelson and Manset-Williamson (2006) was part of the investigation conducted by Manset-Williamson and Nelson (2005) which examined the effect of two reading interventions on reading outcomes [291, 292]. The following study tries to determine the impact of those two interventions on the reading-specific self-efficacy, attributions and affect of students with reading disabilities. Results showed that students receiving the explicit, self regulatory strategy intervention showed greater gains in their attributions to incorrect strategy use for reading failure and the less explicit intervention showed higher reading self-efficacy than the more explicit intervention

Conclusion

Although a relatively large volume of studies about the effectiveness of interventions for children with reading disorders exist, only a few studies met the predefined selection criteria. As discussed earlier in this review the use of randomized controlled trials is not easy to implement in psychosocial research. Nevertheless, since this study aims at advising the Belgian government on how to implement therapy for all patients of the whole country, it seems reasonable to do so starting from the highest level of evidence. Next to the ethical difficulties with the use of RCTs, in some studies children were randomly assigned to tutors that previously had no experience with the experimental conditions. This has a weakness associated with it. Prior to training, these tutors do not have experience with the intervention they are asked to implement which results in poor or different training. As the setting where the intervention took place (general education classrooms, special education classrooms, supplemental reading programs), also can play an important role in outcome they need to be more defined.

In addition, it is very difficult to compare the abovementioned studies, due to differences in severity of reading impairments, duration and severity of treatment, differences in level of skills of the teachers/implementers, age of participants, used measures, setting of implementation…

The conclusion can be drawn, without being the sole one, that some ingredients are essential when developing effective reading programs for reading disabled children. These essential elements include teaching the alphabetic principle (written spelling represents the phonemes in spoken words), promoting phonological awareness (awareness that spoken words are made up of individual sounds) and integration of these elements with activities that develop comprehension and fluency skills.

By searching the different databases, no articles were found concerning the effects and differences between mono- and multidisciplinary treatment. In the included studies, treatment interventions were mainly done by a researcher. Therefore, no conclusions could be formulated about the evidence of the kind and the number of disciplines needed to be incorporated to deliver evidence-based psychosocial treatments. It is also remarkable that no statements could be made about the effectiveness of treatment in comorbid disorders. The included studies only investigated psychosocial treatments within children with the only diagnosis reading disorders'. The co-existence of other comorbid disorders was not mentioned in the description of the subjects in the included studies.

This is noticeable because comorbid disorders are widespread. More research is needed concerning these topics. The mean age of the participants in the included studies is about 8 to 9 years; therefore conclusions about the effectiveness of these psychosocial treatments could only be generalized for this age group.

In general it can be concluded that more in depth research is needed.

The National Guideline Clearinghouse and the Tripdatabase were searched for recent clinical guidelines (2003-2008) for the treatment of children with reading disorders, but no relevant guidelines were found.

3.4.3.3 Mathematical disorders

Introduction

The literaturesearch resulted in only a few articles that met the predefined quality criteria [293]; [294, 295]

Evidence-based interventions for mathematical disorders

Students with learning disabilities often experience deficits in mathematics, especially problem solving difficulties. Next to problems in reading and basic computation skills, difficulties in problem representation and failure to identify relevant information an operation, can influence those mathematical deficits. Recent reviews provide evidence for problem-solving instruction, such as schema-based strategy instruction (focus on conceptual understanding of the problem structure or schemata) in students with learning difficulties (Xin & Jitendra (1999)[296] in Xin, Jitendra, & Deatline-Buchman, 2005). Xin and colleagues (2005) investigated the differential effects of two problem-solving instructional approaches. A group of middle school students with learning difficulties received a schema-based instruction (SBI), where they were taught to identify the problem structure and use a schema diagram to represent and solve the problem, whereas another group received general instruction strategy (GSI). The GSI group learned to draw semiconcrete pictures to represent information in the problem and facilitate problem solving (understand, plan, solve and look back). The SBI group significantly outperformed the GSI group on immediate and delayed posttest, follow-up and on a transfer test. The outcome of this study suggests that classroom instruction, emphasizing on systematic domain-specific knowledge in word problem solving would be beneficial for students with mathematical difficulties. Future research should use more homogenous groups (only mathematical problems). As reading comprehension contributes to student word problem-solving performance, reading levels of the participants should be controlled for [293].

Kroesbergen and van Luit (2002) investigated the effect of guided instruction (GI) and explicit (direct) instruction (DI) in low-achieving students. GI instruction consists of the teacher presenting the problem and encouraging the students to actively search for a possible solution without demonstrating to them a particular strategy.

In the DI instruction the teacher always tells the students how and when to apply which strategy by showing them. Compared to regular instruction, the GI intervention was very effective (improvements on automaticity and multiplication ability). The DI intervention also proved to be more effective than the regular instruction (for automaticity and problem-solving abilities). When GI intervention was compared to the DI intervention, the DI proved to be even more effective and particularly for students' ability to solve multiplication problems.

These findings confirm the assumption that low-achieving students benefit the most from explicit instruction of a relatively small but adequate repertoire of strategies and when and how to apply those strategies [294].

Kroesbergen and colleagues (2004) showed that students with math learning difficulties following the guided instruction intervention, the directed instruction intervention or a regular mathematic curriculum, all improved their strategy use. While the differences between the guided instruction and the direct instruction intervention proved to be small, a few differences were found between the two experimental groups and the control group [295].

Conclusions

The abovementioned studies provide some evidence for the effectiveness of schema-based strategy instruction, direct instruction and guided instruction. Due to the small number of retrieved articles no conclusions can be drawn concerning evidence-based treatment methods for children with mathematical difficulties.

The National Guideline Clearinghouse and the Tripdatabase were searched for recent clinical guidelines (2003-2008) for the treatment of children with mathematical disorders, but no relevant guidelines were found.

Key Points

- **The objective of the literature search was to review the evidence concerning psychosocial interventions for disorders that are treated in Belgian NOK and PSY rehabilitation centres: 'ADHD', 'Pervasive developmental disorders', 'Specific developmental disorders of speech and language' and 'Specific developmental disorders of scholastic skills'.**

IN GENERAL:

- **No articles were found concerning the effects and differences between mono-and multidisciplinary treatment. No conclusions could be formulated about the evidence of the kind and number of disciplines needed to be incorporated to deliver evidence-based psychosocial treatments. It was also remarkable that no statements could be made about the effectiveness of treatment in comorbid disorders.**
- **The terms 'efficacy' and 'effectiveness' are frequently used in the literature review. The original terms of the article were reproduced. The majority of the included studies investigate the 'efficacy' of a particular intervention.**

ADHD:

- **This review is to a large extent based on the review of Pelham and Fabiano (2008). In this review, there are several studies that support behavioural treatments (behavioural parent training, behavioural classroom management and behavioural peer interventions) as well established treatments for ADHD 11..**
- **Except one study, there is found no evidence for office-based psychotherapies conducted solely with the child or cognitive or other child-directed therapies.**
- **It can also be suggested that pharmacotherapy should be the first line intervention in ADHD, with behavioural treatments utilized only after multiple drugs and combinations of drugs have been tried.**

PERVASIVE DEVELOPMENTAL DISORDERS (PDD):

- **Concerning the 'interventions specially created to improve the social interactions', little (imitation sessions and joint attention training) or no (social skills training, specific multimedia and Lego© therapy) evidence was found.**
- **Concerning 'interventions for language and communication', the Picture Exchange Communication System can provide one effective element of a wider 'eclectic' treatment method.**
- **Regarding the 'interventions for restricted, stereotyped, repetitive repertoire of interests and activities', insufficient evidence was also found to support the effectiveness of using 'music therapy' and 'auditory integration training'.**
- **In any intervention program for children with PDD, the principles of applied behaviour analysis could be an important element.**
- **Regarding the 'general early and comprehensive interventions', insufficient evidence was found to support the effectiveness of the interventions 'Parent management training' and the Early Social Interaction Project'.**
- **Finally, several non-traditional treatments for children with PDD have been reviewed, but no single treatment modality has been shown to be evidence-based.**

- **Overall, some general principles seem to be promising. First, a single modal intervention seems not the appropriate way. Second, it seems important to identify children with PDD as early as possible and to start appropriate interventions. Final, interventions seem to be individualized and based on the strengths and needs of the child and his family. Future evaluation must consider which components of these interventions could be combined in a logical way to provide effective 'eclectic' methods of care for children and their families.**

SPECIFIC DEVELOPMENTAL DISORDERS OF SPEECH AND LANGUAGE

- **The only general conclusions that can be drawn concerns the effectiveness of speech and language interventions on children with expressive phonological or expressive vocabulary difficulties, mixed findings in syntax interventions and no to little effects for treatment of children with receptive language difficulties.**
- **There seem to be no differences between the use of trained parents and clinicians as the administrators of the interventions but some studies suggested that parent-based interventions are more effective.**
- **No differences between individual and group therapy were reported.**
- **Some evidence was found concerning phonological awareness training and computer phonological training.**
- **Some evidence was found for lexical interactive intervention and an intervention of elicitation and prompting of words by both clinicians and parents.**
- **Evidence for grammatical interventions was mixed and only one study reported treatment effects after a long, intensive intervention period.**

SPECIFIC DEVELOPMENTAL DISORDERS OF SCHOLASTIC SKILLS

- **Some ingredients are essential when developing effective reading programs for reading disabled children. These essential elements include teaching the alphabetic principle (written spelling represents the phonemes in spoken words), promoting phonological awareness (awareness that spoken words are made up of individual sounds) and integration of these elements with activities that develop comprehension and fluency skills.**
- **For children with mathematical disorders, some studies provide some evidence for the effectiveness of schema-based strategy instruction, direct instruction and guided instruction. Due to the small number of retrieved articles, no conclusions can be drawn concerning evidence-based treatment methods for these children**

4 MULTIDISCIPLINARY REHABILITATION OF THE NOK/PSY TARGET GROUPS IN OTHER COUNTRIES

4.1 INTRODUCTION

This part of the study provides an answer to the question whether the psychosocial treatment of NOK/ PSY target groups in 6 other countries is organized in a multidisciplinary way and how these treatments are funded. Practical constraints of the study limited the number of countries to be compared. The information about the general health care system is relying on the HIT-reports from the WHO-health systems observatory[II]. For the specific organisation of multidisciplinary rehabilitation of the NOK/PSY target groups, the working group decided to contact professional acquaintances in the Netherlands, France, Germany, United Kingdom, Finland and Switzerland. First neighbouring countries were chosen, because of their influence on other West-European countries and more precisely Belgium; second a Scandinavian country was chosen, because Scandinavia is know for its well developed health care and social security system, third and last Switzerland was chosen because it is not part of the European Union but holds a similar prosperity with Belgium. Complementary to Chapter 1, where the Belgian situation is described, this chapter will deal with the practical organisation of health care and multidisciplinary rehabilitation of the NOK/PSY target groups in 6 other countries.

4.2 METHODOLOGY

A quick and dirty literature search of the organisation of psychosocial treatment in the involved countries did not reveal a lot of relevant information. However, reports describing the health care system and/or reform and policy initiatives in progress or under development in some countries are published by the WHO (Health Systems in Transition). These reports provide us with an idea of the organisational structure of the health care system, health care financing and expenditure, provision, development…, but they do not provide valuable information concerning the organisation of psychosocial treatments. The findings are briefly reported for every country in order to provide some background information.

To gather information concerning the organisation of psychosocial treatment, experts in the field were interviewed. A letter including a glossary, as well as a questionnaire (see Appendix to Chapter 5) developed by the research team was sent to experts in the field of the NOK/PSY target groups in the involved countries. The aim of this questionnaire was to get information (based on the expert's knowledge) on the organisation of multidisciplinary rehabilitation of the NOK/PSY target groups in each country. Firstly, the experts were asked to provide information concerning the kind of care providers, whether or not care is organised in a multidisciplinary way and the funding of the costs for this care. When psychosocial treatment is organised in their country in a multidisciplinary way, the experts were asked to rank the organisation forms from the most common to least common. Secondly, in order to check the correctness of the gathered information, the produced documents, obtained from the filled out questionnaires, were resent to the cooperating experts and to other experts in the involved country. The experts of the United Kingdom (Southampton and London) and Switzerland provided extra information. Thirdly, when still only one single expert had provided his/her opinion about the organisation of psychosocial treatment of the target groups in his/her country, additional information was gathered from other professionals in these countries. Professionals from The Netherlands, France, Germany, Scotland, Switzerland and Finland verified the document.

II http://www.euro.who.int/observatory/Hits/20020525_1

Although only a limited number of experts provided his/her opinion concerning the situation in his/her country, the experts were chosen because of their significant authority in the field of developmental disorders, which adds to the reliability of the retrieved information. The names of the experts that consented to publish their name and affiliation can be found in the Appendix to Chapter 4. The information gathered for the abovementioned countries can be compared to the Belgian situation and can invoke issues to discuss. In the United Kingdom regional differences exist, therefore Scotland, Southampton and London were discussed separately.

4.3 RESULTS

4.3.1 Participation

Questionnaires were sent to several experts in the field. All experts were authorities in the field of developmental disorders and involved psychologists, psychiatrists, physicians, university professors… Nevertheless, some caution is necessary in interpreting the results, since only a limited number of experts could provide information. Hence, an influence of personal perceptions or incomplete information of these informants is not excluded.

In Table 34, an overview is provided of the number of "sent" and "received" questionnaires, and of the number of other experts in that country that were contacted ("extra information received", see methodology).

Table 35: Number of sent and received questionnaires

Country	Sent questionnaires	Received questionnaires	Extra information received
France	2	1	2
Germany	3	1	1
The Netherlands	5	1	2
Finland	2	1	1
The United Kingdom	4	3 (of whom 1 from Scotland)	
Switzerland	1	1	1
Total	17	9	6

4.3.2 France

4.3.2.1 General health system

France's health care system is mainly regulated by the state and the statutory health insurance funds. Financing is organised through a national social insurance system complemented by tax-based financing (for example the General Social Tax) and complementary voluntary health insurance. The health insurance covers all households regardless of health status, number of persons, income…. The state sets the ceiling for health insurance spending, amends benefits and regulations and approves reports on health and social security trends. Within the statutory health insurance system there are 3 main schemes: a general (employees in commerce and industry and their families), an agricultural scheme (farmers and their families) and a scheme for self-employed people. In 1999, universal health insurance coverage was developed on the basis of residence in France (99.9% covered for medical expenses). Recently the voluntary health insurance has expanded enormously and is available free to those families with a low income (it covers about 95% of the population). The organisation of health care is centralized with an important role for the regions. Whereas the central authorities define the policy and operational framework, the regions take the responsibility for the organisation and execution of the health care policy.

4.3.2.2 More specific: treatment of target groups

In the Table below, an overview is provided of the care given in France to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 36: Psychosocial Treatment of NOK/PSY target groups in France

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills disorderdisorders of scholastic skills	Private (mono-disciplinary and multidisciplinary)	Social insurance*	Health care
	Neurological paediatrician, child or adolescent psychiatrist	Social insurance*	
	Special education		
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Social insurance	
	Private setting (multidisciplinary)	Social insurance and parents*	Health care
	Neurological paediatrician, child or adolescent psychiatrist	Social Insurance*	
Pervasive developmental disorders	Centre for pervasive developmental disorders (multidisciplinary)	Social insurance	
	Private setting (multidisciplinary)	Social insurance/sometimes parents (in case of experimental setting)	Health care
	Psychiatric setting (multidisciplinary)	Social insurance	
	Special education		
Hyperkinetic disorders	Centres for hyperkinetic disorders (multidisciplinary)	Social Insurance and parents	
	Private setting (multidisciplinary)	Parents	
	Psychiatric setting (multidisciplinary)	*No information*	Health care
	Special education (multidisciplinary)	Social insurance	

* Social insurance funds most interventions but sometimes parents need to pay for treatment as well: when treatment is delivered in a private setting by for example a speech therapist. The treatment provided by a psychomotor therapist in a private setting is completely paid by the parents, as the social insurance does not fund these costs.

4.3.2.3 Setting

The setting where children with the abovementioned disorders in France receive psychosocial treatment is very diverse. Psychosocial treatment is organised in private settings, special education, specific centres[mm] and in psychiatric settings. Children with developmental disorders can also be included in mainstream school (in an ordinary classroom or a special classroom) with special educational aid.

Children with 'Specific developmental disorders of scholastic skills' are treated in a mono-disciplinary, as well as a multidisciplinary way, in a private setting. Mono-disciplinary treatment by a speech therapist (or a physician) or treatment by a neurological paediatrician[nn]/or a child psychiatrist is most common. Multidisciplinary treatment is provided in private settings by different disciplines, in specific centres for children with learning disorders (there are private and associative (semi private) centres, sometimes they are part of a private school), child psychiatric setting or within special education.

Children with 'Specific developmental disorders of speech and language' are treated in special education, private settings, specific centres for children with language disorders and child psychiatric settings.

Part of the treatment concerning speech problems is organized in private settings and part is provided in the specific centres (centre medico psycho pédagogique). Psychosocial treatment is always organised in a multidisciplinary way and involves following disciplines: a physician, a speech therapist, a physiotherapist and a neurological paediatrician[oo].

Children with 'Pervasive developmental disorders' are treated in specific centres for children with pervasive developmental disorders. These autism resources centres are regional centres and involve a multidisciplinary and mobile team specialized in diagnosis/assessment. In collaboration with the psychiatric setting or private setting, they take part in the development of intervention plans. Children with 'Pervasive developmental disorders' can also receive treatment in private settings, child psychiatric settings and special education. Psychosocial treatment is always organised in a multidisciplinary way and involves following disciplines: a psychiatrist, a psychologist, a speech therapist, a physiotherapist, a physician and an occupational therapist.

Children with 'Hyperkinetic disorders' are treated in specific centres for children with hyperkinetic disorders, private settings, child psychiatric settings and special education. Psychosocial treatment is always organised in a multidisciplinary way and involves following disciplines: a neurological paediatrician, a psychologist, a physiotherapist and a psychiatrist.

4.3.2.4 Funding

Psychosocial treatment in France is funded by the social insurance. However, sometimes parents need to pay for treatment as well: when treatment is delivered in a private setting by for example a speech therapist or a neuropsychologist. The treatment provided by a psychomotor therapist in a private setting is completely paid by the parents, as the social insurance does not fund these costs. The responsible department in the government is the department of Health care.

[mm] Some of these centres are specific for children with pervasive developmental disorders, severe dysphasia… but other centres are dealing with all kinds of developmental disorders

[nn] In France, neurological paediatricians are mainly involved in diagnostic procedures and psychoactive drug prescription. Child psychiatrist are also involved in diagnosis and drug prescription but more usually in psychosocial therapy for pervasive developmental disorders, ADHD and other developmental disorders.

[oo] The neurological paediatrician does not provide therapy for speech disorders but he does a part of the initial evaluation.

4.3.2.5 Conclusion

In France, the treatment of children with 'Specific developmental disorders of scholastic skills' is organised in a mono- and multidisciplinary way within private settings, and mono-disciplinary by a speech therapist or a neurological paediatrician or a child psychiatrist. Multidisciplinary treatment is also provided in specific centres for children with learning disorders (there are private and associative (semi private) centres), child psychiatric setting or within special education. For 'Specific developmental disorders of speech and language' it is multidisciplinary organised in private settings, in specific centres, in special education or child psychiatric settings. 'Pervasive developmental disorders' and 'Hyperkinetic disorders' are treated in a multidisciplinary way in psychiatric settings, special education, specific centres and private settings. Some specific centres focus on the treatment of children with pervasive developmental disorders or severe dysphasia, but other centres are treating all kinds of developmental disorders. Social insurances cover the costs for all treatments, except in private settings, where parents need to pay the costs. The responsible department is the department of Health care.

4.3.3 Germany

4.3.3.1 General health system

Decisions concerning the health care system in Germany are made by the federal government, the individual states and designated self-governmental institutions. The responsibilities lay within the membership-based, self regulated institutions of payers and providers of care. The health care system is decentralized and characterized by federalism and delegated to nongovernmental corporatist bodies in the social health insurance system: the physicians' and dentists' association (providers' side) and the sickness funds and their associations (purchasers' side).

The sickness funds raise contributions from their members and their responsibilities include contracting, negotiating prices, quantity and quality insurance measures. These contracts mostly do not cover preventive spa treatment, rehabilitation services and short-term home nursing care.

In order to prevent the sickness funds to refuse people at higher risk for health care services, a risk structure compensation scheme is developed. In this, ambulatory care, care by allied professionals and certain areas of rehabilitation care are included. In order to be able to reimburse from the statutory health insurance, these services need to be prescribed by a physician. Hospitals are represented by organisations based on a private law.

The legislative framework of the social health insurance system, supervision of the corporatist bodies, licensing, performing of scientific consultancy work and provision of information are proposed through health acts, by the Ministry of Health and Social Security. Since 2004, the Federal Joint Committee issues directives relating to all sectors providing care. Although health insurance is compulsory beneath a certain income, citizens have a free choice of sickness funds. Citizens with a higher income can opt out or take a private insurance (substitutive or supplementary to the statutory health insurance).

4.3.3.2 More specific: treatment of target groups

In the Table below, an overview is provided of the care given in Germany to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 37: Psychosocial Treatment of NOK/PSY target groups in Germany

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills	Psychiatric setting (multidisciplinary)	Health insurance[pp]	Education
	Private setting (multidisciplinary)	Parents and other government funding	
	Special education[qq] (multidisciplinary)		
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Other government funding	Education
	Psychiatric setting (multidisciplinary)	Health insurance	
	Private setting (mono-disciplinary)	Parents	
Pervasive developmental disorders	Psychiatric setting (multidisciplinary)	Health insurance	Education and Health
	Private setting (mono-disciplinary)	Parents	
	Special education (multidisciplinary		
Hyperkinetic disorders	Psychiatric setting (multidisciplinary)	Other government funding	Education and Health
	Special education (multidisciplinary)		
	Private setting (multidisciplinary)[rr]	Insurance	

4.3.3.3 Setting

The setting where children with the abovementioned disorders in Germany receive psychosocial treatment is quite uniform. Psychosocial treatment is organised in (child) psychiatric settings, special education or in private settings.

Children with 'Specific developmental disorders of scholastic skills' are treated in a multidisciplinary way in (child) psychiatric settings and receive treatment by a child psychiatrist or psychotherapist, a speech therapist, a physiotherapist, a social worker and the paediatrician (who has also a coordinating function). They also receive multidisciplinary treatment in private settings and in special education.

Children with 'Specific developmental disorders of speech and language' are treated in a multidisciplinary way in special education (provided by a coordinating child psychiatrist/psychotherapist, a speech therapist and a teacher), psychiatric settings (provided by a coordinating child psychiatrist/psychotherapist, a psychologist and a speech therapist). Mono-disciplinary treatment occurs in private settings and is provided by a speech therapist.

Children with 'Pervasive developmental disorders' are treated in a multidisciplinary way in (child) psychiatric settings. The multiple disciplines involve a child psychiatrist/psychotherapist (for coordination and treatment), a psychologist, an occupational therapist, a physiotherapist, a social worker and a teacher. In private settings mono-disciplinary care is provided by a social worker. In special education there is also multidisciplinary care provision.

[pp] If there are comorbidities (as in ADHD for example), training that takes place would be funded by the health insurance.

[qq] Normally the youth welfare office would compensate costs

[rr] If the disorder is diagnosed according to ICD-10 and a request for therapy has been send to the health insurance (public or private) by the therapist, the insurance companies normally cover the costs.

Children with 'Hyperkinetic disorders' receive multidisciplinary treatment in (child) psychiatric settings. The multiple disciplines involve a child psychiatrist/psychotherapist (for coordination and treatment), a psychologist, a speech therapist and a social worker. Multidisciplinary treatment is also provided for these children in private settings and is also organised in special education next to the mainstream school.

4.3.3.4 Funding

The funding of psychosocial treatment for the abovementioned disorders is divers. The costs for children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language' and 'Hyperkinetic disorders' are funded by the department of education. The costs for children with 'Pervasive developmental disorders' are funded by education, but when these children also have a mental disorder, it is funded by the health care. In most cases public and private health insurance will fund interventions/therapies; honorarium for the therapists is negotiated between the public health insurance and the spokesman of the clinicians. Ministry of health is also involved. Parents have to pay a part of the costs. But if children with ADHD are treated, health insurance normally covers all costs.

The responsible department is the department of education, except for children with 'Pervasive developmental disorders having a mental disorder'. In this latter, the department of Health care is responsible.

4.3.3.5 Conclusion

In Germany, multidisciplinary treatment is provided for all target groups, except for 'Specific developmental disorders of speech and language' and 'Pervasive developmental disorders' that can also be treated in a mono-disciplinary way in a private setting. Parents need to pay a part of the costs for treatment. But if children with ADHD are treated, health insurance normally covers all costs. For all target groups, except 'Pervasive developmental disorders', were both the department of health care and education are responsible, the department of education is responsible for the funding.

4.3.4 The Netherlands

4.3.4.1 General health system

In the Netherlands a recent shift occurred from a 'public regulated system' towards a 'regulated market model' in order to provide a more efficient, effective and flexible health care system to handle the fast changing health care needs and demands. Since 1990, two insurance regimes affected the use and right to medical and social care: the 'ziekenfondswet' (ZFW) and the 'Algemene Wet Bijzondere Ziektekosten (AWBZ).Treatments under the ZFW are : medical and surgical treatment; obstetric care, dental care, aids and appliances; non psychiatric hospital admissions; pharmaceuticals; transport, maternity care and care in an audiology centre; costs for generic testing, haemodialysis, chronic recurring respiratory problems, rehabilitation, and services for thrombosis prevention unit. The AWBZ has the responsibility over domestic help, personal care, nursing care, supportive guidance, activating guidance, treatment and accommodation. Since 1996 private health insurance is promoted. The standardized basic coverage ('basisverzekering') is guaranteed for all citizens through the 'Ziekte-Verzekerings-Wet' (health care insurance law) (ZVW). It is responsible for: medical care; dental care for children; specialist dental care for adults; pharmaceuticals; maternity and postnatal care; ambulance and transportation costs; and some medical and paramedical rehabilitation services. Insurance companies are free to decide on the scope of the coverage and premium levels for supplements. The AWBZ will be replaced by the 'wet maatschappelijke ondersteuning' (law societal support, WMO). This WMO will guarantee social support coordinated by the local communities.

In the overall insurance model a separation will be made between chronic and temporary conditions and the medical and paramedical parts of the AWBZ will be transferred to the ZFW. Citizens can benefit from the national compulsory health insurance for 'exceptional medical expenses' (long-term en high-cost care), compulsory sickness funds (when salary is below 30700€) and private health insurance.

The ministry of health, welfare and sport is responsible for the health, health care and social care policies, but local and regional authorities play a complementary role.

4.3.4.2 More specific: treatment of target groups

In

Table 38 an overview is provided of the care given in the Netherlands to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 38: Psychosocial Treatment of NOK/PSY target groups in the Netherlands

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills[ss]	Special education (multidisciplinary)	Social insurance and parents	Health/Welfare and Education
	Mainstream school (multidisciplinary)	Social insurance and parents	
	Psychiatric setting (multidisciplinary)	Social insurance and parents	
	Private setting (multi and mono-disciplinary)	Parents and partly social insurance	
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Social insurance and parents	Health/Welfare and Education
	Mainstream school (multidisciplinary)	Social insurance and parents	
	Psychiatric setting (multidisciplinary)	Social Insurance and parents	
	Private setting (mono-disciplinary and multidisciplinary)	Social insurance and parents	
Pervasive developmental disorders	Special education (multidisciplinary)	Social insurance and parents	Health/Welfare and Education
	Mainstream school (multidisciplinary)	Social insurance and parents	
	Psychiatric setting (multidisciplinary)	Social insurance and parents	
	Private setting (mono- and multidisciplinary)	Parents and Welfare	
Hyperkinetic disorders	Special education (multidisciplinary)	Social insurance and parents	Health/Welfare and Education
	Mainstream school (multidisciplinary)	Social insurance and parents	
	Psychiatric setting (multidisciplinary)	Social insurance and parents	
	Private setting (multidisciplinary and mono-disciplinary)	*No information*	

[ss] Treatment of learning disorders by a private mono-disciplinary working speech therapist will be reimbursable from 1st of January 2009 (www.nvlf.nl)

4.3.4.3 Setting

The setting where children with the abovementioned disorders in The Netherlands receive psychosocial treatment is quite uniform. Psychosocial treatment is organised in special education, mainstream schools, psychiatric settings or in private settings.

Children with 'Specific developmental disorders of scholastic skills' are treated in a multidisciplinary way in special education (provided by a psychologist, a speech therapist, a teacher and a remedial teacher) and in mainstream schools where treatment is provided by a psychologist, a speech therapist and a physiotherapist. Sometimes, when medication is involved, they are treated in a psychiatric setting or a neurological setting. Multidisciplinary and mono-disciplinary treatment is also provided in private settings (multidisciplinary is provided by a specific physician, a psychologist and a speech therapist; mono-disciplinary it is offered by a speech therapist).

Children with 'Specific developmental disorders of speech and language' are treated in a multidisciplinary way in special education and receive multidisciplinary psychosocial treatment offered by a coordinating child psychiatrist, a speech therapist and a teacher. They receive multidisciplinary treatment in mainstream schools (provided by a psychologist, a speech therapist, a teacher and a remedial teacher). Multidisciplinary treatment, provided in psychiatric settings by a psychologist, a speech therapist, a teacher and a remedial teacher and treatment in a private setting also occur, mostly coordinated by the psychologist. Mono-disciplinary treatment is also provided in private settings by a speech therapist).

Children with 'Pervasive developmental disorders' are treated in a multidisciplinary way in special education and receive multidisciplinary psychosocial treatment offered by a physician, a psychologist, a speech therapist, a teacher and a remedial teacher. They receive multidisciplinary treatment in mainstream schools (provided by a physician, a psychologist, a speech therapist and a physiotherapist, mostly coordinated by the psychologist). Multidisciplinary treatment, provided in psychiatric settings by a physician (for treatment), a psychologist, a speech therapist, a physiotherapist and a teacher and multidisciplinary as well as mono-disciplinary treatment in a private settings (multidisciplinary treatment is provided by a physician, a psychologist, a speech therapist, a physiotherapist and a remedial teacher) also occur.

Children with 'Hyperkinetic disorders' are treated in a multidisciplinary way in special education and receive psychosocial treatment offered by a physician (for coordination and treatment), a psychologist, a physiotherapist and a teacher. They receive multidisciplinary treatment in mainstream schools (provided by a physician, a psychologist, a physiotherapist and a teacher, coordinated by a psychologist). Multidisciplinary treatment, provided in psychiatric settings by a physician, a psychologist, a speech therapist, a physiotherapist and a teacher and mono-disciplinary and multidisciplinary treatment in private settings (provided by a physician, a psychologist, a speech therapist and a teacher) also occur.

4.3.4.4 Funding

The funding of psychosocial treatment for the abovementioned disorders is similar for all disorders. The costs for children with 'Specific developmental disorders of scholastic skills' are funded by the social insurance and the parents. The department of health care and the department of education are the responsible departments for this funding. The costs for children with 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders' are funded by the social insurance and the parents (except for the private settings- but since September 2009, parents do not need to pay for treatment by a speech therapist for dyslexia The department of health care is the responsible department for the costs for the treatment of children with 'Hyperkinetic disorders'.

4.3.4.5 Conclusion

In The Netherlands, most target groups are treated in a multidisciplinary way. Mono-disciplinary treatment is however also provided, together with multidisciplinary treatment in private settings for all target groups. Social insurance and the parents pay the costs for treatment (with some exceptions). The department of health/welfare and education is responsible for the funding.

4.3.5 Finland

4.3.5.1 General health system

In Finland the health care system is compulsory, tax-based and provides comprehensive coverage for all citizens, regardless of their financial situation. Public health care services comprise primary health care, provided by municipal health centres, and specialised hospital care. The Ministry of Social affairs and Health is on the national level responsible for the framework legislation on health and social care policy and its implementations. Locally, the municipal health committee, council and executive board decide on planning and organisation of care. They are also responsible for health promotion, disease prevention, primary medical care, medical rehabilitation and dental care. The government social insurance agency (Kansaneläkelaitos, or KELA) provides financial support for health care (more specific: family allowance, student financial aid, maternity allowance, sickness allowance, cash benefits for parents, reimbursement of medical expenses, unemployment benefits, child care, disability allowance, rehabilitation and rehabilitation allowance…) Taxes for this health care system are claimed by the state and municipalities. Recently the private financing has increased.

4.3.5.2 More specific: treatment of target groups

In Table 39, an overview is provided of the care given in Finland to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 39: Psychosocial Treatment of NOK/PSY target groups in Finland

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills	Special education (multidisciplinary)	Education	Health care and Education
	Mainstream school (multidisciplinary)	Education	
	Psychiatric setting (multidisciplinary)	Health care	
	Private setting (multidisciplinary), e.g. therapies, rehabilitation	Health care, social insurance agency (KELA), private insurance agencies	
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Education	Health care and Education
	Mainstream school (multidisciplinary)	Education	
	Private setting (multidisciplinary), e.g. therapies, rehabilitation	Health care, social insurance agency (KELA), private insurance agencies	
	Psychiatric setting (multidisciplinary)	Health care, social insurance agency (KELA)	
Pervasive developmental disorders	Special education (multidisciplinary)	Education	Health care and Education
	Mainstream school (multidisciplinary)	Education	
	Private setting (multidisciplinary), e.g. therapies, rehabilitation	Health care, social insurance agency (KELA), private insurance agencies	
	Psychiatric setting (multidisciplinary)	Health care and social insurance agency (KELA)	
Hyperkinetic disorders	Special education (multidisciplinary)	Education	Health care and Education
	Mainstream school (multidisciplinary)	Education	
	Private setting (multidisciplinary), e.g. therapies, rehabilitation	Health care, social insurance agency (KELA), private insurance agencies	
	Psychiatric setting (multidisciplinary)	Health care, social and private insurance	

4.3.5.3 *Setting*

The setting where children with the abovementioned disorders in Finland receive psychosocial treatment is quite uniform. Psychosocial treatment is multidisciplinary organised in special education, mainstream school, a psychiatric setting or in private settings which can cover neuropsychological or psychiatric orientation depending on the problems of a child.

Children with 'Specific developmental disorders of scholastic skills' are treated in a multidisciplinary way in mainstream school together with special education, a school psychologist, a teacher and a remedial teacher and in mainstream school where treatment is provided by a school or councelling psychologist, a teacher and a remedial teacher. Children receive sometimes neuropsychological rehabilitation organized by neuropsychologist in the private sector or other supportive services provided by a school psychologist or health care and educational care. Multidisciplinary treatment is also provided in private settings (coordinated by a physician) by a psychologist, a speech therapist, an occupational therapist, a physiotherapist, a teacher and a remedial teacher. Sometimes, they are treated in a psychiatric setting and receive treatment by a physician specialized in childhood psychopathology, a psychologist, a social worker, a teacher and a remedial teacher.

Children with 'Specific developmental disorders of speech and language' are treated in a multidisciplinary way in special education. The team: a physician, a psychologist, a teacher and a remedial teacher. These children also commonly receive multidisciplinary psychosocial treatment within a mainstream school by a school psychologist, a speech therapist, a teacher and a remedial teacher. Treatment in a private setting is provided in a multidisciplinary way (coordinated by a school physician), by professionals specialized in rehabilitation of problems concerned. Multidisciplinary treatment, provided in a psychiatric setting also occurs. This treatment is coordinated by a school physician and school psychologist.

Children with 'Pervasive developmental disorders' are treated in a multidisciplinary way in special education and receive multidisciplinary psychosocial treatment offered by a psychologist, a speech therapist, a teacher or a remedial teacher. They receive multidisciplinary treatment in the mainstream school by a psychologist, a teacher and a remedial teacher.

Multidisciplinary treatment, provided in a private setting is coordinated by a physician, and is given by a psychologist specialized in either neuropsychology or psychotherapy, a speech therapist, or an occupational therapist. In a psychiatric setting their treatment is planned by multiprofessional team consisting of a physician (for coordination and treatment), a psychologist, a teacher and a remedial teacher. Other services also provide treatment: paediatrics, paediatric neurology, department of language pathology and a neuropsychiatric setting.

Children with 'Hyperkinetic disorders' are treated in a multidisciplinary way in mainstream school provided by a school psychologist, a teacher or a remedial teacher, in special education provided by a psychologist, an occupational therapist, a teacher and a remedial teacher. Multidisciplinary treatment, provided in a private setting is organised by a physician (for coordination), a psychologist, an occupational therapist, a teacher or a remedial teacher. In a psychiatric setting multidisciplinary treatment is provided for these children by a physician (for coordination), a psychologist, a teacher and a remedial teacher.

4.3.5.4 *Funding*

The funding of psychosocial treatment for the abovementioned disorders is quite similar over all disorders.

When children with 'Specific developmental disorders of scholastic skills' receive multidisciplinary treatment in special education, mainstream school or a psychiatric setting this is funded by a combination of health care (25%) and educational care (75%). When children go to a private setting, the costs are funded by a combination of health care (90%), private insurances (1 to 5%) and social insurance agency (KELA) (5 to 10 %).

When children with 'Specific developmental disorders of speech and language' receive multidisciplinary treatment in special education, this is funded by a combination of health care (95%) and social insurance agency (5%). Multidisciplinary treatment in mainstream school is funded by a combination of health care (>90%) and other sources (<10%). Treatment in a private setting is funded by a combination of health care (75%) and governmental social insurance (25%). In a psychiatric setting treatment is funded by the health care.

When children with 'Pervasive developmental disorders' receive multidisciplinary treatment of any kind in special education, the costs are funded by a combination of health care (20%), educational care (40%) and social insurance (20%). Treatment in a private setting is funded by a combination of health care (75%), social insurance agency (20%) and private insurance (5%). Treatment within mainstream school is funded by a combination of health care (70%), educational care (10%) and social insurance agency (20%). In a psychiatric setting the costs are funded by a combination of health care (90%) and social insurance (10%).

When children with 'Hyperkinetic disorders' receive treatment in special education, this is funded by a combination of health care (90%), social insurance agency (5%) and private insurance (5%). Treatment in mainstream school is funded by a combination of health care (95%) and social insurance agency (5%). Treatment in a private setting or a psychiatric setting is funded by a combination of health care (90%), social insurance (20 %) and private insurance (5%).

The department responsible for these funding are the same for all disorders, namely the department of health care and the department of education. Also the department of social affairs is occasionally involved in some cases.

4.3.5.5 Conclusion

In Finland, all target groups are treated in a multidisciplinary way, the costs are paid rather similarly for each disorder (see earlier) and the department of health care, education and the social insurance agency (KELA) are the main responsible agencies for the funding.

4.3.6 The United Kingdom

4.3.6.1 General health system

In the United Kingdom publicly funded health care is provided to all citizens (financed entirely or in majority part by taxes instead of through private payments made to insurance companies or directly to health care providers)[tt]. The National Health Service is mainly funded through general taxation (direct taxes, value-added tax and employee income contributions), local taxation (funding for social services). As further is mentioned for Scotland, the organisation and funding of health care in the United Kingdom is a devolved matter (England, Scotland and Northern Ireland each have its own system). Although the public National Heath Service system dominates the health care in the UK, private health care and a wide variety of alternative and complementary treatments are available. However, coverage of costs is available to 100% of the population. Health care services are delivered through public providers and responsibilities are left to local bodies, like the primary care trusts (PCTs) in England.

4.3.6.2 More specific: treatment of target groups in Southampton

In Table 40, an overview is provided of the care given in Southampton to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

[tt] http://en.wikipedia.org/wiki/Healthcare_in_the_United_Kingdom

Table 40: Psychosocial Treatment of NOK/PSY target groups in Southampton

Disorder	Setting	Funding Parents do not pay fees	Responsible department
Specific developmental disorders of scholastic skills	Special education (multidisciplinary)	Government funding	Department of health, education and social services
	Mainstream school (multidisciplinary)	Government funding	
	Psychiatric setting (multidisciplinary)	The health department	
	Private setting (multidisciplinary)	Funded privately but each child is paid for by usually a combination of health, social services and education	
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Government funding	Department of health, education and social services
	Mainstream school (multidisciplinary)	Government funding	
	Private setting (multidisciplinary)	Funded privately but each child is paid for by usually a combination of health, social services and education	
Pervasive developmental disorders	Special education (multidisciplinary)	Government funding	Department of health, education and social services
	Mainstream school (multidisciplinary)	Government funding	
	Psychiatric setting (multidisciplinary)	The health department	
	Private setting (multidisciplinary)	Funded privately but each child is paid for by usually a combination of health, social services and education	
Hyperkinetic disorders	Psychiatric setting (multidisciplinary)	The health department	Department of health, education and social services
	Special education (multidisciplinary)	Government funding	
	Mainstream school (multidisciplinary)	Government funding	

4.3.6.3 Setting (Southampton)

The setting where children with the abovementioned disorders in the United Kingdom (Southampton) receive psychosocial treatment is quite similar. Psychosocial treatment is always multidisciplinary organised and is provided in special education, mainstream schools, psychiatric settings and private settings.

Children with 'Specific developmental disorders of scholastic skills' are going to mainstream schools and special education, where they receive multidisciplinary treatment provided by a physician (for coordination and treatment), a psychologist, a speech therapist, an occupational therapist, a physiotherapist, a social worker, a tutor, a teacher, a remedial teacher and a child psychiatrist. Sometimes children are referred to psychiatric settings to receive multidisciplinary treatment from a child psychiatrist (for coordination and treatment), a psychologist and a social worker. These children rarely receive multidisciplinary psychosocial treatment within private settings by a child psychiatrist, a community paediatrician, a psychologist, a speech therapist, an occupational therapist, a physiotherapist, a social worker, a tutor, a teacher and a remedial teacher.

Children with 'Specific developmental disorders of speech and language' are treated in a multidisciplinary way in mainstream schools (by a psychologist and a speech therapist) and in special education (provided by a community paediatrician (for coordination), a psychologist, a speech therapist, a teacher and a remedial teacher). Rarely, these children receive treatment in private settings (provided by a paediatrician (for coordination and treatment), a psychologist, a speech therapist, a tutor, a teacher and a remedial teacher).

Children with 'Pervasive developmental disorders' go to mainstream schools (when mild pervasive developmental disorder, syndrome of Asperger, is diagnosed) and are treated in a multidisciplinary way in by a community paediatrician or a child psychiatrist, a psychologist, a speech therapist, an occupational therapist, a physiotherapist, a social worker, a tutor, a teacher and a remedial teacher. In special education multidisciplinary treatment is provided by a community paediatrician (for coordination) or a child psychiatrist, a psychologist, a speech therapist, and a teacher. Very few children go to psychiatric settings, only short term, mainly for behavioural problems (longer if there are forensic issues). Treatment is provided by a physician (for coordination and treatment), a psychologist, a speech therapist and an occupational therapist. Private settings also provide multidisciplinary treatment for children with 'pervasive developmental disorders' (provided by a community paediatrician or a child psychiatrist (for coordination and treatment), a psychologist, a speech therapist, an occupational therapist, a physiotherapist, a social worker, a tutor, a teacher and a remedial teacher), but are not often chosen for.

Children with 'Hyperkinetic disorders' are treated in a multidisciplinary way in mainstream schools by a community paediatrician, a child psychiatrist, a psychologist or a remedial teacher. When these children have learning disabilities (IQ below 70) and/or behavioural difficulties, they go to special education and receive multidisciplinary treatment by a community paediatrician (for coordination) or a child psychiatrist, a psychologist, a tutor, a teacher and a remedial teacher. Very few children go to psychiatric settings, only short term, mainly for behavioural problems (longer if there are forensic issues). Treatment is provided by a child psychiatrist (for coordination and treatment), a psychologist, a social worker and a tutor

4.3.6.4 Funding (Southampton)

All educational, health and social services are funded by the government through different departments: health care, education and social services on a national level, but are delivered by funding local health trusts, social services departments or educational departments. Some local authorities are trying to develop joint budgets. Some of the Hampshire child mental health services are run and funded by such a joint budget. Parents do not need to pay anything for the costs of the treatments, only when they choose to sent their children to a private school.

4.3.6.5 *Conclusion*

In Southampton, all target groups are treated in a multidisciplinary way. The departments of health, education and social services are responsible for the funding of psychosocial treatment of all mentioned target groups and parents do not need to pay for the costs of treatment.

4.3.6.6 *More specific: treatment of target groups in London*

In Table 41 an overview is provided of the care given in London to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 41: Psychosocial Treatment of NOK/PSY target groups in London

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills	Mainstream school (mono-disciplinary)	Other governmental funding	Education
	Special education (mono-disciplinary)	Other governmental funding	
	Private setting	Parents	
Specific developmental disorders of speech and language	Special education (multidisciplinary)	Other governmental funding	Health/Welfare and Education
	Mainstream school (multidisciplinary)	Other governmental funding	
	Psychiatric setting (multidisciplinary)	Other governmental funding	
	Paediatrics (multidisciplinary)	Other governmental funding	
Pervasive developmental disorders	Mainstream school (multidisciplinary)	Other governmental funding	Health/Welfare and Education
	Special education (multidisciplinary)	Other governmental funding	
	Psychiatric setting (multidisciplinary)	Other governmental funding	
	Paediatrics (multidisciplinary)	Other governmental funding	
Hyperkinetic disorders	Mainstream school (multidisciplinary)	Other governmental funding	Health/Welfare and Education
	Psychiatric setting (multidisciplinary)	Other governmental funding	
	Paediatrics (mono-disciplinary)	Other governmental funding	
	Special education (multidisciplinary)	Other governmental funding	

4.3.6.7 *Setting (London)*

The setting where children with the abovementioned disorders in the United Kingdom (London) receive psychosocial treatment is quite uniform. Psychosocial treatment is organised in (special) education, private settings, psychiatric settings and paediatric settings. Special education is provided both by extra resources in mainstream schools and in special units. The choice is made by local departments of education on the basis of the severity of educational needs. Parents are consulted and decisions can be reviewed by tribunals.

Children with 'Specific developmental disorders of scholastic skills' are treated in a mono-disciplinary way in mainstream schools but also in special education or in private settings. These treatments can be strengthened by a psychologist, a teacher, a tutor or a remedial teacher.

Children with 'Specific developmental disorders of speech and language' are treated in a multidisciplinary way in (special) education, but also in psychiatric settings or paediatric settings. The involved disciplines are: a physician (for research and coordination), a psychologist, a speech therapist, a tutor and a remedial teacher.

Children with 'Pervasive developmental disorders' are treated in a multidisciplinary way provided by (child) psychiatric settings, as part of the special education. Sometimes this is provided by the paediatric settings as well. Less often, both settings provide multidisciplinary help in the mainstream schools. Multidisciplinary organised treatment in mainstream schools organised by special education is also an option. A physician (coordination and treatment), a psychologist, an occupational therapist, a physiotherapist, a tutor, a teacher and a remedial teacher are the important members of the team.

Children with 'Hyperkinetic disorders' receive multidisciplinary treatment in (special) education organised by psychiatric settings or paediatric settings. Special education can also organise treatment within mainstream schools. The team exists of a physician (coordination and treatment), a psychologist, a teacher and a social worker.

4.3.6.8 Funding (London)

Health treatments are provided through the NHS and are governmental funded but this is not the same as the governmental department of Health. The NHS is a national agency and it provides the whole funding. Parents do not have to pay anything. Except for the private treatment of children with 'Specific developmental disorders of scholastic skills': this treatment is paid by the parents. The responsible departments of the government are the department of health/welfare and the department of education.

4.3.6.9 Conclusion

In London, all target groups are treated in a multidisciplinary way, except for children with 'Specific developmental disorders of scholastic skills' who receive mono-disciplinary treatment in mainstream school and in special education. Children with 'Hyperkinetic disorders' can also receive mono-disciplinary treatment in paediatrics. The department of education is responsible for the funding of psychosocial treatment of children with specific developmental disorders of scholastic skills and the departments of health/welfare and education are responsible for the funding of psychosocial treatment of all other mentioned target groups. Parents do not need to pay for the costs of treatment, except for children going to private education.

4.3.7 Scotland

4.3.7.1 General health system

There are significant differences in how the National Health Service (NHS) works between the different countries of the UK. The National Health Service (NHS) in Scotland[uu] is one of the three national health systems in the UK. Both, government-based (e.g. department of Health, General Medical Council…) and non-governmental-based services (e.g. Royal colleges) regulate health care in Scotland. The NHS in Scotland is managed by the Scottish Government's Department for Health and Community Care. Its role includes: setting national objectives and policies on health, holding NHS Scotland accountable for its performance against these national objectives and intervening when serious problems arise that cannot be solved locally. Health services in Scotland are divided in primary care (covers everyday health services such as GP's surgeries, dentists and opticians) and secondary care (refers to specialised services such as hospitals, ambulances and mental health provision). There are 14 regional NHS Health Boards in Scotland.

[uu] http://www.scot.nhs.uk/

Each Health Board has one or more Community Health Partnerships (CHPs) responsible for the planning and development of primary care services in its area.

Next to improving the health of local communities, they also organise community based services in health centres, clinics and schools (health visits, district nursing, speech and language therapy, physiotherapy, podiatry, mental health, addiction and learning disability services).The NHS is funded through general taxation. There is also a small private health care sector in Scotland. People pay for that private health care either through insurance or when they use its services.

4.3.7.2 More specific: treatment of target groups

In Table 42, an overview is provided of the care given in Scotland to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

Table 42: Psychosocial Treatment of NOK/PSY target groups in Scotland

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills	Mainstream education (multidisciplinary)	Social insurance	Education
	Special education (multidisciplinary)	Social insurance	
	Private setting (mono-disciplinary)	Parents	
Specific developmental disorders of speech and language	'Health'[vv] (Mental Health care, mono-disciplinary)	Social insurance	Health care
	Mainstream school (mono-disciplinary)	Social insurance	
	Special education (mono-disciplinary)	Social insurance	
	Private setting (mono-disciplinary)	Social insurance	
Pervasive developmental disorders	Mainstream school (multidisciplinary)	Social insurance	Health care and Education
	Special education (multidisciplinary)	Social insurance	
	Psychiatric setting (multidisciplinary)	Social insurance	
	Private setting (multidisciplinary)	*No information*	
Hyperkinetic disorders	Psychiatric setting (multidisciplinary)	Social insurance	Health care
	Paediatrics (multidisciplinary)	Social insurance	
	Mainstream school (multidisciplinary)	Social insurance	
	Special education (multidisciplinary)	Social insurance	

[vv] Child & adolescent Mental Health Services (CAMHS) are a part of this organisation

4.3.7.3 Setting

The setting where children with the abovementioned disorders in Scotland receive psychosocial treatment is quite divers. Psychosocial treatment is multidisciplinary organised in mainstream schools, special education, in private settings or in psychiatric settings.

Children with 'Specific developmental disorders of scholastic skills' are treated in a multidisciplinary way in mainstream schools and in special education .

Treatment is provided by a teacher and a remedial teacher. They can also receive mono-disciplinary treatment in private settings by a tutor.

Children with 'Specific developmental disorders of speech and language' are treated in a mono-disciplinary way in Child & Adolescent Mental Health Services (CAMHS) by a speech therapist. These CAMHS are a part of the coordinating organisation 'Health'. In mainstream schools, special education and private settings they receive mono-disciplinary treatment by a speech therapist.

Children with 'pervasive developmental disorders' are treated in a multidisciplinary way in mainstream schools by a physician (for coordination and treatment), a psychologist, a speech therapist, an occupational therapist, a teacher and a remedial teacher. In special education they receive multidisciplinary psychosocial treatment offered by a physician (for coordination of treatment), a psychologist, a speech therapist, an occupational therapist, a teacher and a remedial teacher Multidisciplinary treatment, provided in psychiatric settings by a physician (for coordination of treatment), a psychologist, a speech therapist and an occupational therapist also occurs. Private settings and paediatrics also provide treatment for children with 'pervasive developmental disorders'.

Children with 'Hyperkinetic disorders' are treated in a multidisciplinary way in psychiatric settings (provided by a physician (for coordination of treatment), a psychologist, an occupational therapist and a nurse), in private settings (provided by a physician (for coordination of treatment), a psychologist, an occupational therapist, a teacher and a remedial teacher) and in mainstream schools (provided by a physician (for coordination of treatment and advice), a psychologist, an occupational therapist, a teacher, a remedial teacher and a nurse). In special education they receive treatment by a physician (for coordination of treatment and advice), a psychologist, an occupational therapist, a teacher, a remedial teacher and a nurse. Multidisciplinary treatments, in paediatrics also occur (provided by a physician (for coordination of treatment) and a nurse).

4.3.7.4 Funding

The costs of psychosocial treatment for 'Specific developmental disorders of scholastic skills' are funded by the social insurance, except for treatments in a private setting (where the parents are responsible for the costs).

The costs of psychosocial treatment for 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders' are funded by the social insurance.

The department of education is responsible for the funding of the treatment for children with 'Specific developmental disorders of scholastic skills' and treatment for children with 'pervasive developmental disorders'. The department of health care is responsible for the funding of treatment for children with 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'.

4.3.7.5 Conclusion

In Scotland children with 'Pervasive developmental disorders' and 'Hyperkinetic disorders' are treated in a multidisciplinary way. Children with 'Specific developmental disorders of speech and language' are treated in a mono-disciplinary way and children with 'Specific developmental disorders of scholastic skills' are treated multidisciplinary, except in private settings. The department of health care is responsible for the funding of treatment for children with 'Specific developmental disorders of speech and language' and 'Hyperkinetic disorders'. The department of education is responsible for the funding of psychosocial treatment of children with 'developmental disorders of scholastic skills' and both departments are responsible for the funding of psychosocial treatment of 'Pervasive developmental disorders'. Costs are paid by the social insurance and the parents only need to pay for treatment of their children with 'Specific developmental disorders of scholastic skills' when they are going to private settings.

4.3.8 Switzerland (Zurich)

4.3.8.1 General health system

The Federal Health Insurance Act is responsible for the regulation of health care in Switzerland[ww]. The health insurance is compulsory for all citizens in Switzerland. This insurance covers treatments (the costs of medical treatment and hospitalization) and is set out in the Federal Act. However, the insured person pays part of the cost of treatment. This is done by means of an annual excess (or deductible, called the *franchise)* and by a charge of 10% of the costs over and above the excess. The Swiss health care system is a combination of public, subsidized private and totally private systems. Compulsory insurance can be supplemented by private "complementary" insurance policies, which allow for coverage of some of the treatment categories not covered by the basic insurance. For the compulsory health insurance the companies can not set any conditions relating to age, sex or state of health for coverage. Social health insurance is supervised by the Federal Office of Public Health, but the complementary insurance is supervised by the Federal Office for Private Insurance.

4.3.8.2 More specific: treatment of target groups

In Table 44, an overview is provided of the care given in Switzerland (Zurich) to children with 'Specific developmental disorders of scholastic skills', 'Specific developmental disorders of speech and language', 'Pervasive developmental disorders' and 'Hyperkinetic disorders'. The remark should be made, that the findings from this overview can not be generalized to Switzerland as only information about the provision of psychosocial treatment in Zurich was obtained.

ww http://en.wikipedia.org/wiki/Healthcare_in_Switzerland

Table 43: Psychosocial Treatment of NOK/PSY target groups in Switzerland (Zurich)

Disorder	Setting	Funding	Responsible department
Specific developmental disorders of scholastic skills	Mainstream school (multidisciplinary)	Community through school budgets	Education
	Special education (multidisciplinary)	Community through school budgets	
	Private setting (mono-disciplinary)[xx]	Health Insurance/parents	
Specific developmental disorders of speech and language	Mainstream school (mono-disciplinary)	Community through school budgets	
	Special education (mono-disciplinary)	Community through school budgets	
	Private setting (mono-disciplinary)	Parents	
Pervasive developmental disorders	Special education (multidisciplinary)	Community and social insurance	
	Private setting (multidisciplinary)	Health insurance	
	Mainstream school (multidisciplinary)	Community and social insurance	
	Psychiatric setting (multidisciplinary)	Health insurance	
Hyperkinetic disorders	Mainstream school (multidisciplinary)	Community and social insurance	
	Special education (multidisciplinary)	Community and social insurance	
	Psychiatric setting (mono-disciplinary)	Health insurance	
	Private setting (mono-disciplinary)	Health insurance	

4.3.8.3 Setting

The setting where children with the abovementioned disorders in Switzerland (Zurich) receive psychosocial treatment is quite uniform. Psychosocial treatment is organised in mono-as well as-multidisciplinary way in mainstream schools, special education, private settings and psychiatric settings.

Children with 'Specific developmental disorders of scholastic skills' are treated in a multidisciplinary way in mainstream schools. Depending on the needs of each child, treatment is provided by a speech therapist, a remedial teacher and/or a psychomotor therapist. In special education, treatment is provided depending on the needs of each child, by a speech therapist, an occupational therapist, a physiotherapist and/or a remedial teacher. Rarely, mono-disciplinary treatment is provided in private settings and is offered by a psychologist, a speech therapist or an occupational therapist.

[xx] Costs for treatment within private settings are mainly paid by the parents

Children with 'Specific developmental disorders of speech and language' are treated in a mono-disciplinary way in mainstream schools, special education and rarely in private settings. The treatments are provided by a speech therapist. The speech therapist is connected to the schools.

Children with 'Pervasive developmental disorders' are treated in a multidisciplinary way in special education (depending on the needs of each child, treatment is provided by a physician (for coordination, treatment and evaluation), a psychologist, a speech therapist, an occupational therapist, a teacher and/or a remedial teacher). When children go to mainstream schools, they receive multidisciplinary treatment organized by school services, depending on the needs of the child, by a physician (for coordination, treatment and evaluation), a psychologist, a speech therapist, an occupational therapist, a teacher and a remedial teacher. In psychiatric settings, multidisciplinary treatment is offered by a physician (for coordination, treatment and evaluation) and a psychologist. Rarely, treatment is provided in private settings by a physician (for coordination, treatment and evaluation) and a psychologist.

Children with 'Hyperkinetic disorders' go to mainstream schools and receive multidisciplinary treatment organized by school services. They receive also treatment in special education. Both of these services provide treatment, depending on the needs of the child, by a physician (for coordination, treatment and evaluation), a psychologist, a teacher and a remedial teacher). Mono-disciplinary treatment organised by a private setting or a psychiatric setting is provided by a physician (for coordination, treatment and evaluation) or a psychologist.

4.3.8.4 Funding

Treatment for children with 'Specific developmental disorders of scholastic skills' and 'Specific developmental disorders of speech and language', provided by mainstream schools and special education are funded through school budgets. These school budgets are provided by the communities who raise taxes for this funding.

Mainstream schools and special education providing treatment for children with 'Pervasive developmental disorders' and 'Hyperkinetic disorders', are funded by the community. For private schools some are financially supported by the communities/government and some are not, thus the parents have to pay different amount of school money. Some disorders (listed on a special list) are paid by the social insurance. This is provided on a national level (involves 'invalidity, inborn disorders, unemployment benefits, pension…) and the parents do not pay any of the costs.

Treatment in private settings for children with the abovementioned disorders, except children with 'Specific developmental disorders of speech and language' (where the parents pay the costs) are funded by the social or health insurance. Treatments in a psychiatric setting are also funded by the social or health insurance. This health insurance is obliged for all citizens. The health insurance does not cover the complete costs for treatment because parents need to pay a small part of the costs themselves.

The department of education is responsible for all funding of treatment of the abovementioned disorders.

4.3.8.5 Conclusion

In Switzerland, children with 'Pervasive developmental disorders' receive multidisciplinary treatment and children with 'Specific developmental disorders of speech and language' receive mono-disciplinary treatment. Treatment for children with 'Specific developmental disorders of scholastic skills' is organised in a multidisciplinary way (except in private settings) and for children with 'Hyperkinetic disorders' it is also organized in a multidisciplinary way (except in psychiatric and private settings). The department of education is responsible for the funding of psychosocial treatment of all target groups. Parents need to pay a part of the costs for treatment in psychiatric and private settings, except for treatment of children with 'Specific developmental disorders of speech and language' in private settings (where the parents pay the costs).

4.4 CONCLUSION

In Table 44, an overview is outlined concerning settings providing mono-or multidisciplinary psychosocial treatments of NOK/PSY target groups in other countries and Table 45 outlines an overview of the funding and responsible departments involved in these treatments.

NOK/PSY rehabilitation centres, as we know them in Belgium do not exist in the involved countries.

Most of these countries however, provide multidisciplinary care for children with 'Specific developmental disorders of scholastic skills', except in The Netherlands, France, Scotland and Switzerland (multi- but also mono-disciplinary care when treated in private settings) and in London (only mono-disciplinary treatment).

Children with 'Specific developmental disorders of speech and language' are also mostly treated in a multidisciplinary way, except in The Netherlands and Germany (multi- but also mono-disciplinary care when treated in private settings) and in Scotland and Switzerland (only mono-disciplinary treatment).

For children with 'Pervasive developmental disorder' multidisciplinary treatment is provided in all these countries, except in The Netherlands and Germany (multi- but also mono-disciplinary care when treated in a private setting).

Multidisciplinary treatment is provided in most countries for children with 'Hyperkinetic disorders', except in Switzerland in psychiatric and private settings. In The Netherlands treatment is provided in both mono-and multidisciplinary way in private settings.

For the kind of disciplines and the number of disciplines provided in other countries, most countries reported multidisciplinary treatment offered by mainly physicians, (child) psychiatrists, paediatricians, psychologists, speech therapists, occupational therapists, physiotherapists, social workers and (remedial) teachers

These children can appeal to a variety of services: mainstream schools, special education, psychiatric and private settings are delivering psychosocial treatment. These findings are in line with the provision in Belgium, where treatment can be provided by special education and parallel services outside the school (for example rehabilitation centres), but also by child psychiatric services and by private settings. We assume that a similar system of care and the gradation of care also exist in other countries.

The financing of 'Specific developmental disorders of scholastic skills' is often the responsibility of the department of Education alone, except in The Netherlands, Finland and Southampton where it is the responsibility of both the department of Health care and the department of education, and in France where it is the department of Health that is responsible.

The responsibility of the financing of psychosocial treatments belongs to similar departments across the countries for 'Pervasive developmental disorders'. This is organized mainly by the department of health care together with the department of education, except in France (funded by the department of health care alone); and Switzerland (funded by the department of education alone).

Whereas the responsibility for financing of 'Specific developmental disorders of speech and language' and of 'Hyperkinetic disorders' at first sight is rather similar, for the latter Health Insurance is more often involved in reimbursement.

Mostly, and similar to the Belgian situation, parents pay a small part of the costs through health or social insurances. In Southampton parents do not need to pay anything. When parents are responsible for the complete cost of the treatment, it concerns mainly treatment in private settings.

Key points

- **Because of the methodology of this chapter, conclusions should be treated with caution.**
- **Although no rehabilitation centres such as the Belgian NOK/PSY centres, exist in the discussed countries, children with 'Pervasive developmental disorders' almost always receive multidisciplinary treatment.**
- **Children with 'Hyperkinetic disorders' are also mostly treated in a multidisciplinary way (except in some settings in Switzerland, where they are treated in a mono-disciplinary way),**
- **Children with 'Specific developmental disorders of scholastic skills' are often treated in a multidisciplinary way (except in London, where only mono-disciplinary treatment is available),**
- **Children with 'Specific developmental disorders of speech and language' are often treated in a multidisciplinary way (except in Scotland and Switzerland, where they can only be treated in a mono-disciplinary way)**
- **The responsibility of the financing for 'Pervasive developmental disorders' and 'Hyperkinetic disorders' is mainly organized by the department of health care together with the department of education. The financing of 'Specific developmental disorders of scholastic skills' and 'Specific developmental disorders of speech and language' is mostly the responsibility of the department of Education alone,**
- **In most cases, treatment costs are partially paid by the parents (in private setting they sometimes pay the complete cost) but in some of the countries treatment is completely free.**

Table 44: Overview of settings providing psychosocial treatment for NOK/PSY target groups in other countries and their mono- or multidisciplinary character (based on information from a limited number of experts, see Methodology 4.3.1)

		France	Germany	The Netherlands	Finland	Scotland	Southampton	London	Switzerland
Specific developmental disorders of scholastic skills									
	Mainstream school	/	/	multi	multi	multi	multi	mono	multi
	Special education	Multi	multi	multi	multi	multi	multi	mono	multi
	Psychiatric setting	/	multi	multi	multi	/	multi	/	/
	Private setting	Mono and multi	multi	mono and multi	multi	mono	multi	mono	mono
	Other	Neurological paediatrician/child or adolescent psychiatrist	/	/	/	/	/	/	/
Specific developmental disorders of speech and language									
	Mainstream school	/	/	multi	multi	mono	multi	multi	mono
	Special education	Multi	multi	multi	multi	mono	multi	multi	mono
	Psychiatric setting	Multi	multi	multi	multi	/	/	multi	/
	Private setting	Multi (and mono)	mono	mono	multi	mono	multi	/	mono
	Other	Neurological paediatrician/child or adolescent psychiatrist	/	/	/	'Health-CAMHS' (mono)	/	paediatrics (multi)	/
Pervasive developmental disorders									
	Mainstream school	/	/	multi	multi	multi	multi	multi	multi
	Special education	Multi	multi	multi	multi	multi	multi	multi	multi
	Psychiatric setting	Multi	multi	multi	multi	multi	multi	multi	multi
	Private setting	Multi (and mono)	mono	mono and multi	multi	multi	multi	/	multi
	Other	Centre for PDD (multi)	/	/	/	/	/	paediatrics (multi)	/
Hyperkinetic disorders									
	Mainstream school	/	/	multi	multi	multi	multi	multi	multi
	Special education	Multi	multi	multi	multi	multi	multi	multi	multi
	Psychiatric setting	Multi	multi	multi	multi	multi	multi	multi	mono
	Private setting	Multi and mono	multi	mono and multi	multi	multi	(Not filled out)	/	mono
	Other	Centre for Hyperkinetic disorders	/	/	/	/	/	paediatrics (multi)	/

Table 45: Overview of funding and departments involved for psychosocial treatments for NOK/PSY target groups in other countries (based on information from a limited number of experts, see Methodology 4.3.1)

		France	Germany	The Netherlands	Finland	Scotland	Southampton	London	Switzerland
Specific developmental disorders of scholastic skills	Funding	Social insurance/ parents	Other government funding/ parents Psychiatric settings by health insurance	Social insurance/ parents	Health care/private and social insurancy agence KELA	Social insurance	Government funding	Other government funding/ parents	Community and social/health insurance/ parents
	Department	Health care	Education	Health/ Welfare and Education	Health care and Education	Education	Health, education and social services	Education	Education
Specific developmental disorders of speech and language	Funding	Social insurance/ parents (private setting)	Other government funding/ parents Psychiatric settings by health insurance	Social insurance/ parents	Health care/private and social insurancy agence KELA and private insurance	Social insurance	Government funding	Other government funding	Community through school budgets/ Parents
	Depart	Health care	Education	Health/ Welfare and Education	Health care and Education	Health care	Health, education and social services	Health/Welfare and Education	Education
Pervasive developmental disorders	Funding	Social insurance/sometimes parents (in case of experimental setting)	Health Insurance/Parents	Social insurance/ parents	Health care/private and social insurancy KELA	Social insurance	Government funding	Other government funding	Community insurance/ social insurance/ health insurance
	Department	Health care	Education and Health care	Health/ Welfare and Education	Health care and Education	Health care and Education	Health, education and social services	Health/Welfare and Education	Education
Hyperkinetic disorders	Funding	Social insurance/	Other	Social	Health	Social	Government	Other	Community

		parents (private setting)	governmental funding Psychiatric settings by health insurance	insurance/ parents	care/private and social insurance agency KELA	insurance	funding	government funding	insurance/ social insurance/ health insurance
	Depart	Health care	Education	Health/ Welfare and Education	Health care and Education	Health care	Health, education and social services	Health/Welfare and Education	Education

4.5 CONCLUDING REMARKS: COMPARISON TO THE BELGIAN SITUATION

This chapter on international organisation of care for the target groups of NOK/PSY centres relies on expert opinion only; and although efforts were made to cross-check the results, they should be treated with some caution.

Like Belgium, all European countries studied in the study, have multidisciplinary treatment available for developmental disorders in children. This is standard in all countries for pervasive developmental disorders and for hyperkinetic disorders; it is often, but not always, available for developmental disorders of scholastic skills and for developmental disorders of speech and language. Often, "multidisciplinary" means "two or more disciplines" (instead of three or more disciplines).

However, the organisational context of the multidisciplinary treatment is rather unique in Belgium: none of the six countries relies on multidisciplinary rehabilitation centres recognised and regulated by the government to provide this therapy. Usually educational services and/or child psychiatric services are in charge; sometimes also private multidisciplinary teams are available. Often, private (monodisciplinary) therapists are an alternative.

Reimbursement is usually available, and in some countries parents don't pay anything. Usually the charge is shared by the department of education, and health or social insurance. Sometimes the educational department is almost fully in charge of the 4 indications under study. Differences exist between the categories "learning disorders" or "speech/language disorders" on the one hand; and pervasive or hyperkinetic disorders on the other hand. For the latter, health insurance is more often involved in reimbursement.

Thus, the question is not so much "if" multidisciplinary therapy is available, but "where" it is available.

In Belgium, currently a large experience with multidisciplinary treatment for developmental disorders is available in the rehabilitation sector. Nevertheless, teamwork including therapists and/or psychologists and/or BAMAs in educational sciences and/or medical doctors is also available in child psychiatric services, centres for mental health care, and in special education. Special multidisciplinary day centres exist as well, often for infants and toddlers. In Dutch mainstream schools, since a few years, "care coordinators" coordinate between all involved parties (parents, teacher, school psychologists of the CLB or "Centra voor Leerlingen Begeleiding", private therapist, and so on) for children with diverse difficulties. Diagnostic possibilities for young children with a suspicion of developmental disorders exist in the Dutch "Centra voor Ontwikkelingsstoornissen"; and for some of the developmental disorders (pervasive developmental disorders, cerebral palsy) multidisciplinary diagnostic and therapeutic advice is provided in tertiary reference centres in university hospitals. Additionally, remedial teachers (zorgleerkrachten) and in the Dutch schools the "GON supervisor" (GON begeleider) provide help, although not necessarily in a multidisciplinary way. Neither should the efforts be forgotten of many self-help groups (e.g. "Zit Stil" for hyperkinetic disorders).

It was not the purpose of this study to describe comprehensively all possible services available for children with developmental disorders, especially since it is not possible to know how many of the children in these services also belong to the NOK/PSY target groups.

If a better system to describe the population in the NOK/PSY centres is adopted, ideally it would be shared by the other players in the field, in order to provide a better view on what kind of problems are dealt with by which services. Only then, thorough and clear-cut planning would be possible.

5 COST/ OUTCOME STUDY

5.1 INTRODUCTION

As it is difficult to estimate the size and cost of the consumption of rehabilitation care for the patients, a preliminary cost/outcome study was performed in order to initiate further research. However, since gathering information about these costs and size of consumption for the complete rehabilitation would be too time-consuming taken the scope of the present study, this pilot study was limited to children with 'Specific developmental disorder of scholastic skills'. Children with 'Specific developmental disorders of scholastic skills' were chosen because of the high frequency of this index disorder in the data sample (see Chapter 2 data analyses) and specific instruments are available to evaluate outcome (which is less the case for other disorders as for example for hyperkinetic disorders or pervasive developmental disorders). The main goals of this study were to provide an overview of the total cost of rehabilitation for children with learning disorders, by a non-random sample (the rehabilitation centres were chosen randomly, but the children receiving treatment in these centres were not chosen randomly). This was done from the perspective of the parents as well as from the perspective of the payers (RIZIV/INAMI and other governmental authorities providing reimbursement for childhood disabilities). Another aim of the outcome study concerns the evolution in outcome as a consequence of the treatment. Due to the small sample size, this cost/outcome study should be seen as a 'pilot study'. It is set up to investigate the feasibility of the methodology and the usefulness of information. The data and conclusions resulting form this cost/outcome study are preliminary and ask for further research.

5.2 METHODOLOGY

5.2.1 Participants

For the Dutch speaking rehabilitation centres, the working group decided to question patients with 'Specific developmental disorders of scholastic skills' (F81) as an index disorder. Due to the lower prevalence of patients with 'Specific developmental disorders of scholastic skills' (F81) as an index disorder in the French speaking rehabilitation centres, the working group decided to involve patients with F81 as index or co-morbid disorder in these centres. As no German speaking rehabilitation centres were involved in his study, no information could be gathered from these centres. Children with 'Specific developmental disorders of scholastic skills' were chosen because of the high frequency of this disorder and the availability of outcome measures. Patients needed to be in rehabilitation for at least one year and to receive treatment or to have ended their treatment recently, in order to make an outcome evaluation possible. This evaluation is only achievable by the yearly provided reports from each patient. National Health services ask that for every patient, a yearly report is formulated and sent to the advising physicians, in order to make renewal of therapy possible. There is a relative freedom concerning the tests used in these report: a limited list of test exists that includes some obligations for specific target groups. A RIZIV working group is working out more harmonization.

5.2.2 Procedure

Twenty rehabilitation centres were randomly drawn from the database but stratified according to the relative prevalence of the two principal languages (Dutch and French). A minimum of 100 patients were expected to participate in this study. This number of participants would be enough for this pilot study to show preliminary results and provide information for further research. From the 20 rehabilitation centres, 12 centres were Dutch speaking centres and 8 centres were French speaking centres. The selected rehabilitation centres were informed about the aim of the study (see Appendix to Chapter 5).

A week after sending this information letter, the rehabilitation centres were contacted by phone to ask for their participation. The participating centres received a package with 10 pilot-tested questionnaires (see further) and envelopes. Afterwards the centres were contacted regularly in order to guarantee cooperation. The collection of data took place between April and June 2008. Because of practical considerations, first the Dutch speaking rehabilitation centres were dealt with; the French speaking rehabilitation centres were dealt with later.

All patients meeting the abovementioned criteria received an envelope with an informed consent and a questionnaire from the rehabilitation centres. The parents, guardians or a tutor of the child were asked to fill out the informed consent and questionnaire and to put it in the enclosed envelope. This envelope was returned back to the rehabilitation centres and the reports and invoices of the patients were sent to the researchers. The collected data were treated confidentially by the researchers.

Every rehabilitation centre, as well as every patient, got an identification number. This last number was linked to the identification number of the rehabilitation centre. On every envelope, the identification number of the centre and of the patient was written by the researchers. So, the rehabilitation centres wrote the same number on the reports and the invoices. This procedure guarantees that the researchers know which questionnaires, reports and invoices are from the same patient without threatening the confidentiality.

5.2.3 Questionnaire and informed consent

In Appendix to Chapter 5 the Dutch and French questionnaires, developed by the research team, are presented. The questionnaire comprises five parts. The first part consists of general questions about the child with a specific developmental disorder of scholastic skills. The second part deals with questions about the type and frequency of treatment given in the rehabilitation centre. In a third part, strengths and weaknesses of the child were assessed by the Strength and Difficulties Questionnaire [SDQ] (Goodman, 1997)yy. This questionnaire was chosen because it assesses often co-morbid behavioural problems in children with learning disorders and it can also be used as a follow-up measure in future research (asking for the effects of an intervention)zz. Further questions related to the subjective evaluation of the impact of the rehabilitation therapy on the functioning of the child.

The fourth part comprised questions on health care utilization outside the rehabilitation centre, use of social care and other non-medical resources were asked. Finally there were some questions on socio-demographic and economic characteristics of the parents. Rehabilitation centres were asked to provide the invoices from all participating patients (in order to calculate the total cost of rehabilitation for this group of patients) and the evaluation reports of these patients (the onset and midterm and/or end report of the patients). In order to give an opinion about the evaluation of the outcome, the onset reports were compared with the end reports taking into account the duration of therapy. Percentiles of the tests were used in order to make statements concerning the outcome of the therapy. These percentiles are frequently used in scientific literature and provide a scale on which a child can be compared with peers.

Filling out the questionnaire takes about one hour. In the informed consent (in Appendix to Chapter 5) the parent, guardian or tutor declares to know, having read and understand the purpose of this research and gives his permission to the rehabilitation centres to send the reports and the invoices to the researchers. Finally, the parent, guardian or tutor needs to agree that the collected data will be used for research in a confidential manner.

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yy http://www.sdqinfo.com/

zz Carroll, J.M., Maughan, B., Goodman, R. & Meltzer H. (2005). Literacy difficulties and psychiatric disorders: evidence for co-morbidity, Journal of Child Psychology and Psychiatry, 46(5), pp 524–532

5.2.4 Response

Of the Dutch speaking centres 83% (n=10) agreed to participate and 62.5% of the French speaking centres (n=5) agreed to participate. Part of the non-participation is due to the fact that in 3 French speaking rehabilitation centres no children with 'Specific developmental disorder of scholastic skills' were treated. In 2 of the participating French speaking centres only 6 and 2 children were treated for this disorder. As we already saw in chapter 2 data analyses, the main index codification (ICD-10 registration) learned that developmental disorders of scholastic skill make up 21.8% of all disorders treated in the Dutch speaking centres but only 6.1% in the French speaking centres. This discrepancy can point to differences in the type/severity of patients treated in the rehabilitation centres in both parts of our country and should be taken into account when results are interpreted.

Information concerning cooperation of the centres is provided in Table 46. Finally 127 questionnaires were sent to these centres[aaa]. By the end of June 2008, 88 of the 127 questionnaires given to parents/guardians or tutors were returned. This brings the response rate to 69%, which is quite high for this type of study. Of the 88 received questionnaires, 17 (19.3%) were from Walloon centres. The lower proportion of returned questionnaires from the Walloon centres stems from the fact that learning disorders are much less frequently treated in those centres (see Chapter 2 data analyses). Moreover the time span for the parents to respond was shorter.

Table 46: Number of participating centres, distributed and received questionnaires

Province	Number of participating centres	Number of distributed questionnaires	Number of received questionnaires
East-Flanders	5	47	33
West-Flanders	3	28	28
Antwerp	1	10	6
Brabant	1	8	4
Hainaut	3	26	11
Liège	2	8	6
Total	15	127	88

5.3 RESULTS

5.3.1 Statistics

Information on treatment and costs is summarized in this section. All calculations were performed using the statistical package SPSS, version 14.0 for windows.

The results of these analyses are only illustrative. The sample size is far too small to derive any conclusions; no thorough analyses are therefore performed. The results should give an indication for the usefulness of further research in this field.

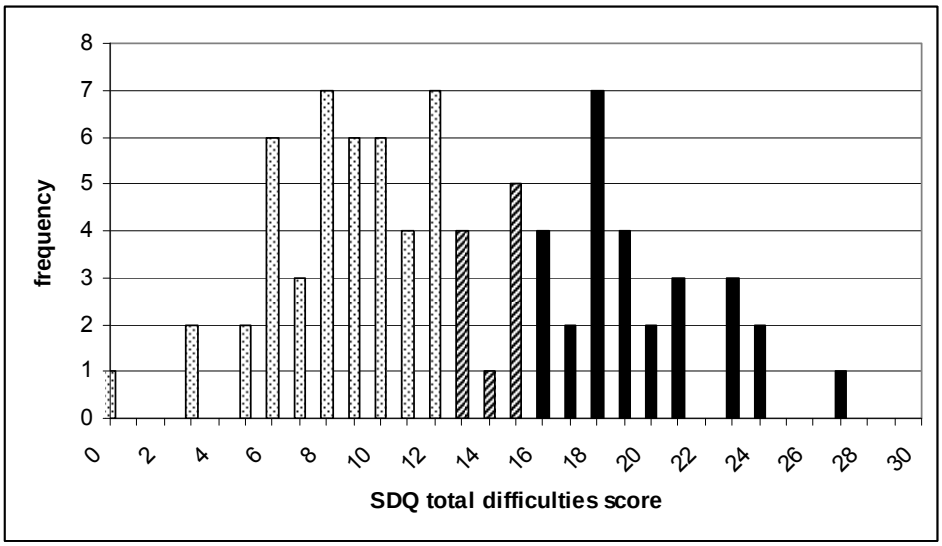
aaa We intended to distribute 150 questionnaires – 10 per centre – but did not meet this level because some rehabilitation centres did not have enough patients meeting the predefined criteria (one year in rehabilitation and 'Specific developmental disorders of scholastic skills' as a disorder in French centres or as an index disorder in Dutch centres).

5.3.2 Characteristics of the respondents

The children in the sample are between 8 and 14 years old. The male/female ratio is 1.3/1. Most of the respondents indicate multiple morbidities for the children: 62 (71.3%) have dysorthographia, 57 (65.5%) have dyslexia, 52 (59.8%) have dyscalculia and 11 (12.6%) have AD(H)D. In 62.1% of the cases the diagnosis was made when the child was between 6 and 8 years old. Most of the children (94.3%) are in primary school including 6.9%, who follow special primary education, 57.7% did not pass one or more years.

The Strengths and Difficulties Questionnaire (SDQ), a behavioural screening questionnaire, was administered to the parents. The total SDQ-scores of the children are summarized in Figure 2. The total difficulties score is in the 'normal range' (0-13) for 58.5% of the children (dotted bars), in the 'borderline range' (14-16) for 12.2% (bars with stripes) of the children and in the abnormal range for 29.3% of the children (fully coloured bars). Most frequent abnormal values are for the hyperactivity score (40%) and for the emotional symptoms score (37.6%). Results show 19.8% abnormal values for the peer problems score, 11.6% for the conduct problems score and 6% for the pro-social behaviour score. There is an indication that SDQ-scores are higher and with more abnormal values in the French rehabilitation centres. A mean value of the total SDQ-score of 12.4 and 25% abnormal values (>16) for the Dutch questionnaires (n = 71) versus an average of 15.6 and 50% abnormal values for the French questionnaires (n = 17), was obtained.

Figure 2: Histogram of parent completed SDQ questionnaire



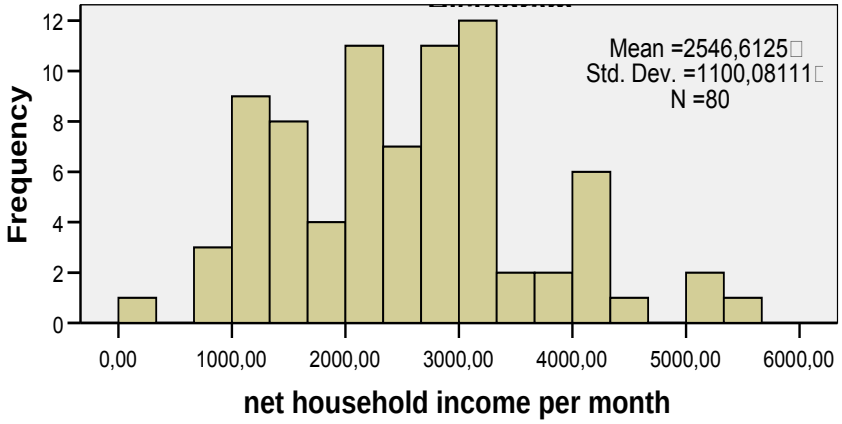
5.3.3 Socio-economic characteristics of the households

All but one questionnaire are filled out by the parents; mostly by the mother (85.9%). Most respondents (78.8%) are married or live together; 21.2% are single. Concerning the work situation, 23.8% of the respondents are not working; 65.5% are working as an employee and 10.7% are self-employed. Only 28.2% of those working are working full time. The partners of the respondents are working more: only 11.8% is not working and 66% works as an employee. Only 7% are working less than full time.

Most of the children (58.9%) are living in 3- or 4-person households and 8.3% in households of less than 3 persons. In 42.4% of the households, there are 2 children, in 24.7% only 1 and in 22.4% there are 3 children. In 17.9% of the cases the highest educational level in the household is lower secondary education or less. At the other end of the scale there are 16.3% household with a higher (university or non-university) educational level. The educational level is higher in the Flemish households.

Total net household income per month was also asked. First the respondents were asked to give the total net household income per month. In a follow-up question, respondents who did not give their exact income, were asked to situate their income in a predefined set of intervals. Both questions were combined to derive household income: the exact income amount was taken whenever it was given and the midpoint value of the interval was used otherwise. Only 10% of income data were missing. The mean net household income amounts to €2550 (a standard deviation of 1100); the full distribution is shown in Figure 3. 14% of children receive increased child allowancesbbb.

Figure 3: Average net household income per month: a histogram



5.3.4 Treatment given in the rehabilitation centre

5.3.4.1 Treatment from the perspective of the parents

In Appendix to Chapter 5, a table summarizes the information on the treatment given in the rehabilitation centre. As can be seen, speech therapy is the most frequent type of therapy given in the rehabilitation centre: 97.6% of all children in the sample receive this therapy, mostly once or twice a week, individually for 1 hour. The next most frequent therapy is occupational therapy: 76.5% of the children in the sample receive occupational therapy in the rehabilitation centre, on average about once a week for 50 minutes. Physiotherapy and psychotherapy are given to respectively 54% and 48% of the children. Contact with other professionals is very infrequent.

If the different types and frequencies of therapies are aggregated, a child has on average 13 therapy sessions per month (with a minimum of 5 and a maximum of 26). The total therapy duration per child per month amounts to 646 minutes (more than 10 hours). The minimum is 270 minutes and the maximum 1200. Due to missing observations however less than half of the sample (43%) remains for these calculations. This can be the result of the degree of complexity of the questionnaire.

5.3.4.2 Treatment from the perspective of the rehabilitation centres (invoices)

On the basis of the invoices, an additional insight in the amount of therapy and its costs can be obtained. The rehabilitation centres retrieved the invoices of the children for about a whole year ccc . The average monthly consumption and cost from this information was calculated (see Table 47).

bbb The amounts of increased child allowances received are €70,30 (N = 3), €93,63 (N = 4) 360,66 (N = 1), €218,49 (N = 3) and € 410,10 (N = 1).

ccc For 34 children the information related to 1 year, for 44 children it was > 12 months; for 10 children it was < 1 year: see table

number of months	2	3	5	6	7	8	11	12	13	14	15	16	18
frequencies	1	2	1	3	1	1	1	34	35	6	1	1	1

The children in our sample visit the rehabilitation centre on average 6.4 times a month with an average of 8 lump sums (forfait) chargedddd. The average total cost (i.e. costs to the patient and to the RIZIV/INAMI) of the therapy in the rehabilitation centre amounts to €651 per month. Most of this cost is reimbursed by the health insurance institute (RIZIV/INAMI) (€643.2). On average, the patient only pays €8 per month. There is some variability between the patients, but this seems to be less than for other medical cost studies: standard deviations are about one third of the mean whereas in other studies they often are as large as the meaneee. For the average total cots for example, the minimum cost we encountered is €368 and 80% of the children have costs below €771. Only 10% of children have average total rehabilitation centre costs above €954. Percentile values of the different variables are presented in Table 47. A graphical presentation of the distribution of the total cost is in Figure 4.

Table 47: Average amount of therapy given in the rehabilitation centre and average cost per patient per month: some descriptive statistics

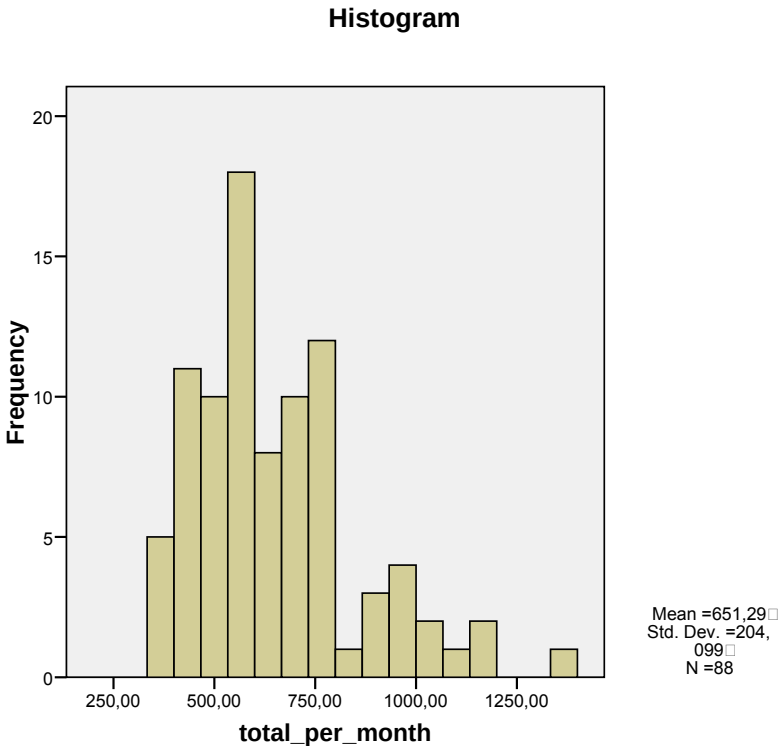
		Average number of sessions	Average number of lump sums	Average cost reimbursed by RIZIV/INAMI	Average patient charge	Average total cost
N	Valid	88	88	88	88	88
	Missing	0	0	0	0	0
Mean		6.4450	8.0282	643.2274	8.0614	651.2888
Median		6.1667	6.9414	587.5371	8.7488	600.0570
Mode		5.69(a)	6.00	360.28(a)	.00	368.08(a)
Std. Deviation		1.73054	5.63121	204.03231	4.47632	204.09947
Minimum		3.36	4.00	360.28	.00	368.08
Maximum		12.00	56.01	1380.15	23.77	1398.00
Percentiles	10	4.8401	5.1326	404.4714	.0000	410.1472
	20	5.1641	5.7993	465.5795	5.2813	475.9032
	30	5.5269	6.1374	529.1397	7.5641	534.3391
	40	5.8200	6.5633	557.6723	8.1515	566.8870
	50	6.1667	6.9414	587.5371	8.7488	600.0570
	60	6.3846	7.4654	662.1603	9.4235	668.4303
	70	6.7750	8.4153	729.5569	9.7081	733.0509
	80	7.6423	9.2927	758.7658	10.6587	770.9156
	90	8.5154	10.7933	951.3426	12.5521	954.9761

a Multiple modes exist. The smallest value is shown

ddd One lump sum is charged for treatment of the child during 1 hour.

eee M. T. French, M. P. Mundt, M. Fleming & S. K. Zavala, The cost of medical care for patients with diabetes, hypertension and both conditions: does alcohol use play a role? Journal of Internal Medicine 2005; 258: 45–54; Conigliani C, Tancredi A. 2005. Semi-parametric modelling for costs of health care technologies. Statistics in Medicine 24: 3171-3184; Billingsley Kaambwa, Stirling Bryan, Pelham Barton, Hilda Parker, Graham Martin, Graham Hewitt, Stuart Parker and Andrew Wilson, Costs and health outcomes of intermediate care: results from five UK case study sites, Health and social care in the community, 2008, early online view; McCrone, Paul; Heslin, Margaret; Knapp, Martin; Bull, Paul; Thompson, Alan, Multiple Sclerosis in the UK: Service Use, Costs, Quality of Life and Disability, PharmacoEconomics, Volume 26, Number 10, 2008 , pp. 847-860(14); Paladino, Joseph A. , Martin H. Adelman, Jerome J. Schentag and Paul B. Iannini, Direct Costs in Patients Hospitalised with Community-Acquired Pneumonia After Non-Response to Outpatient Treatment with Macrolide Antibacterials in the US, Pharmacoeconomics 2007; 25 (8): 677-683; De Graeve Diana, Joseph Peuskens, Benoît Gillain, Adelin Albert, Nele Debackere, Betty Van Vleymen. A description of direct medical costs in patients with schizophrenia and initiated on haloperidol, olanzapine or risperidone. Acta Psychiatrica Belgica, 2007, vol 107(4): 31-39.

Figure 4: Average total cost per patient per month in the rehabilitation centre: a histogram



The sample size and study design is not adequate enough for further investigation of the relationships between the variables. However, a positive correlation between the information on duration and frequency of therapy collected from the parents via the questionnaire and the information collected from the centres via the invoices was foundfff. This is reassuring and suggests that the information given by the respondent is adequate. On the other hand, given that invoices are available, there is not much need to bother the respondents with these questions. The results further suggest that patients (n=17) treated in the French speaking rehabilitation centres receive more intensive (and hence more costly) therapy. In the French part on average patients visit the centres 7.4 times per month with 9.2 lump sums charged; the total bill generated amounts to €768. The corresponding Dutch figures (n=71) are 6.2 times, 7.8 lump sums and a bill of €623. There is no difference detected according to SDQ-values (the total bill for patients with total SDQscore >16 amounts to €663 in comparison to €661 for patients with normal SDQscores). Lower treatment costs in the rehabilitation centre are observed for households with a higher educational level.

5.3.5 Evaluation of the treatment

5.3.5.1 Evaluation of the treatment from the perspective of the parents

Some questions in the questionnaire are related to the subjective evaluation of the changes of the behaviour of the child with respect to functioning at school, emotional and social functioning. The responses are tabulated in Table 48. For all items that are based on numeric values the raw score was used.

fff The Pearson correlation coefficient between the number of therapy sessions to the centre per month (questionnaire) and the average total cost of treatment in the rehabilitation centre (invoices) equals .491 (significant at the .01 level, two-tailed); the Pearson correlation coefficient between the total therapy duration in the centre per month (questionnaire) and the average total cost of treatment in the rehabilitation centre (invoices) equals .599 (significant at the .01 level, two-tailed).

More respondents evaluate the evolution of the child in a positive sense. This is especially the case for functioning at school, self reliance and confidence of the child. Some respondents also added remarks expressing appreciation for the therapy given in the rehabilitation centre.

Table 48: Subjective evaluation of the improvement of the child

	Totally untrue	*Untrue*	Neutral	True	Totally true	Don't know	Not appl	Mis-sing
*Since the start of the therapy in the rehabilitation centre, do you observe **improvement** with respect to **functioning at school** in the following fields*								
Math (a)	*2 2.5%*	*1 1.2%*	10 12.4%	**34 41.9%**	**33 40.7%**	1 1.2%	3	4
Language (b)	*1 1.2%*	*0 0%*	9 10.8%	**36 43.4%**	**35 42.2%**	2 2.4%	3	2
Courses other than (a) or (b)	*2 2.5%*	*1 1.3%*	16 20.0%	**40 50.0%**	**19 23.8%**	2 2.5%	4	4
Focus	*2 2.5%*	*7 8.6%*	18 22.2%	**38 46.9%**	**14 17.3%**	2 2.5%	4	3
Making homework	*1 1.2%*	*7 8.3%*	18 21.4%	**42 50.0%**	**15 17.9%**	1 1.2%	1	3
Enjoy going to school	*3 4.1%*	*3 4.1%*	30 41.1%	**19 26.0%**	**17 23.3%**	1 1.4%	13	2
*Since the start of the therapy in the rehabilitation centre, do you observe **changes** with respect to **emotional functioning** in the following fields*								
Less fear	*2 2.9%*	*8 11.8%*	26 38.2%	**23 33.8%**	**6 8.8%**	3 4,4%	18	2
Less frequently angry	*5 7.5%*	*11 16.4%*	24 35.8%	**22 32.8%**	**5 7.5%**	0 0%	18	3
Less outbursts of anger	*3 5.6%*	*12 22.2%*	15 27.8%	**17 31.5%**	**6 11.1%**	1 1.9%	31	3
Less frequently sad	*3 4.8%*	*13 21.0%*	19 30.7%	**19 30.7%**	**7 11.3%**	1 1.6%	24	2
Worried less	*2 2.9%*	*13 18.6%*	22 31.4%	**27 38.6%**	**6 8.6%**	0 0%	16	2
Less sleeping problems	*5 9.1%*	*14 25.5%*	13 23.6%	**13 23.6%**	**6 10.9%**	4 7.3%	32	1
More confident	*3 3.7%*	*9 11.0%*	19 23.2%	**41 50.0%**	**10 12.2%**	0 0%	4	2
Less complaints (headache, stomachache…)	*3 5.6%*	*9 16.7%*	17 31.5%	**18 33.3%**	**4 7.4%**	3 5.6%	33	1
*Since the start of the therapy in the rehabilitation centre, do you observe **changes** with respect to **social functioning** in the following fields*								
Is less baited	*4 7.5%*	*8 15.1%*	21 39.6%	**16 30.2%**	**1 1.9**	3 5.7%	34	1
Has more friends	*3 3.6%*	*6 7.2%*	28 33.7%	**18 21.7%**	**5 6.0%**	3 3.6%	23	2
Is more cheerful	*4 4.7%*	*5 5.9%*	22 25.9%	**33 38.8%**	**7 8.2%**	1 1.2%	14	2
Is less aggressive	*5 5.9%*	*5 5.9%*	23 27.1%	**12 14.1%**	**6 7.1%**	1 1.2%	34	2
Is more self-reliant	*4 4.6%*	*3 3.4%*	20 23.0%	**41 47.1%**	**12 13.8%**	0 0%	7	1
Is more assertive	*5 5.8%*	*3 3.5%*	25 29.1%	**34 39.5%**	**11 12.8%**	1 1.2%	8	1

5.3.5.2 *Evaluation of the treatment from the perspective of the rehabilitation centres (reports)*

In general

As mentioned earlier, percentiles were used in order to draw conclusions about the outcome after therapy. When several tests were conducted, average scores (percentiles) were calculated and discussed. These results were obtained after both researchers independently scored the results from the reports and after they agreed on a corresponding score. Results from these analyses (comparing the percentiles across tests) should be interpreted cautiously, as a heterogeneous group of tests were administered within each tested domain in the involved rehabilitation centres. In Appendix to Chapter 4 an overview is provided of all tests that were mostly used in the rehabilitation.

After comparing the domains (technical reading, reading comprehension, orthography, mathematics and context rich mathematical problems) of the onset report with the midterm or end report, no general conclusions could be drawn due to the quite high proportion of missing values. Sometimes, the rehabilitation centres did not consistently test the same domains at onset and at midterm or at the end of the therapy. Another problem was the use of wrong norm groups (e.g. a child of 12 years old is compared with a norm group of 9 years old) that made the conversion to percentiles impossible. These findings do not mean that these problems are often occurring, but when only 88 children were incorporated in this study, conclusions should be drawn with care. It was not the aim of this pilot study do go into more detail on these matters. Despite these restrictions some descriptive results are reported. When progress is reported it should be interpreted cautiously because no control group was incorporated.

Since the aim of this pilot-study was only to verify the feasibility of this kind of research, other domains like psychomotor skills, attention, socio-emotional factors, although very important, were not included in further analyses. Also, whereas scholastic skills (and psychomotor skills) were frequently re-evaluated after a certain time period and could be retrieved from the reports, this was less the case for domains like attention and socio-emotional factors.

The average total intelligence coefficient in the onset report is 91[ggg] (minimum 69 and maximum 120). The average performal IQ is 91[hhh] (minimum 52 and maximum 121). The average verbal IQ is 93[iii] (minimum 47 and maximum 125). This is based on data from 74 patients (TIQ) and 71 patients (VIQ and PIQ). For the total intelligence coefficient is the 25th percentile 82 and the 75th percentile 99.

Analyses comparing the total intelligence coefficient between Dutch speaking centres and French speaking centres, showed respectively an average of 93 and 80. Again, this should be viewed with caution, due to the low numbers of included patients.

Due to differences in time between onset reports, midterm and/or end reports, the analyses were standardized and based on a time period of 1 year therapy in a rehabilitation centre. In Table 50 an overview is outlined of the average, minimum and maximum gains after one year of therapy.

ggg There were 14 missing values.
hhh There were 17 missing values.
iii There were 17 missing values.

Table 49: Average, minimum and maximum gains on the different domains

Domain	Possible comparisons*	Average gain (percentiles)	Minimum (percentile)	Maximum (percentile)
Technical reading	39/88 (44.3%)	+5	-38	+76
Reading comprehension	16/88 (18.2%)	+5	-43	+58
Orthographics	49/88 (55.7%)	+11	-28	+61
Mathematics	51/88 (58.0%)	+7	-29	+99
Context rich mathematical problems	5/88 (5.7%)	+10	0	+23

* Comparisons made for children with at least 2 evaluations on different times during the rehabilitation process

By language of the rehabilitation centres

When the abovementioned analyses were conducted separately for the Dutch speaking centres and the French speaking centres the following results outlined in Table 50, were found.

Table 50: Average, minimum and maximum gains in Dutch and French speaking centres

	Dutch speaking rehabilitation centres				French speaking rehabilitation centres			
Domain	Possible comparisons*	Average gain (percentiles)	Minimum(percentile)	Maximum (percentile)	Possible comparisons*	Average gain (percentiles)	Minimum (percentile)	Maximum (percentile)
Technical reading	35/71 (49.3%)	+1	-38	+45	4/17 (23.5%)	+33	0	+76
Reading comprehension	16/71 (22.5%)	+5	-43	+58	/	/	/	/
Orthographics	47/71 (66.2%)	+11	-28	+61	2/17 (11.7%)	+2	+1	+3
Mathematics	46/71 (64.8%)	+7	-29	+54	5/17 (29.4%)	+10	-15	+99
Context rich mathematical problems	5/71 (7.0%)	10	0	+23	/	/	/	/

* Comparisons made for children with at least 2 evaluations on different times during the rehabilitation process

It can be concluded that a great difference is perceived between the average gain and the minimum and maximum gain. In addition to this, there were some missing values and inconsistencies. Therefore, results are quite unreliable and no further analyses were made linking the outcome scores based on the reports, the SDQ-scores and the subjective evaluation of the improvement of the child by the parents to the costs.

The careful conclusion could be drawn that most of the children made gains on the abovementioned domains (based on the average gain after one year of therapy, which varied from 1 to 11 percentile gains). The clinical (or 'educational') significance of a gain of e.g. 11 percentiles as compared to the norms of the different tests used, is difficult to interpret and actually not known.

5.3.6 Treatment and costs on top of the treatment in the rehabilitation centre[jjj]

5.3.6.1 Medication

A quite high percentage of children (29.9%, N = 26) in our sample are taking 1 or more drugs[kkk]: 24 children take drugs for concentration or hyperactivity, 1 child for asthma and 1 for epilepsy. When only the drug costs related to hyperactivity/concentration are retained, the average drug cost per month paid by the patient amounts to €2.2. Patient costs vary between €1 and €70 for those patients who incur costs, i.e. only 37% of the sample. For 63% of the patients, no costs were incurred (see Table 51).

Table 51: Frequencies of total patient cost for medication due to learning disorder

€	Frequency	Percent
0	63	76.8
0.01 - 5.00	9	11.0
5.01- 10.00	8	9.8
10.01- 70.00	2	2.4
Total	82	100.0
System Missing	6	

5.3.6.2 Therapy outside the rehabilitation centre

Therapy outside the rehabilitation centre is very rare and is recorded very incompletely and inconsistently. Only 7 children indicate they use therapy outside the rehabilitation centre. However in the follow-up question to specify a positive answer, 9 respondents filled in some kind of therapy. Three respondents indicate their child followed psychotherapy outside the rehabilitation centre once a month; other information on the therapy is incomplete. Three respondents (1 overlapping) indicate their child followed speech therapy (further information incomplete). Four respondents indicated their child followed 'other therapy': one therapy with an optometrist; one unspecified, one therapy from a teacher of integrated education and finally one from the (ordinary) teacher. On the basis of this information it is clear that the costs related to these therapies outside the rehabilitation centre is limited; not enough information is available to calculate a more precise figure.

One third of the children get special attention at school: 30.7% from their teacher and 30.8% from the remedial teacher. In all but one case, children who get this help are in lower (mainstream) education. Two children receive speech therapy at school and 1 child visits a school psychologist. Other assistance is also given by the GON-teacher[lll] (3 children), the school head (1 child), 1 respondent mentions STICORDI[mmm] measures as special help and 1 respondent does not specify the type of help.

Most parents (83%) help their child with his/her homework, on average about half an hour per day[nnn]. Some respondents (25%) spent less than 15 minutes a day, while at the other end of the scale 29% of the respondents spent one hour or more per day (see Table 52).

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jjj Although parents were asked about the extra costs they make for their child with a learning disorder, no information was obtained of complementary and alternative medicine. Possibly more information could have been obtained if the questionnaire specificly asked about the use of these medicines.

kkk There was 1 missing value.

lll GON stands for Integrative education. These GON-teachers are often, against their original purpose, used as remedial teachers. The GON-teacher, working in special education, should provide teachers in mainstream school with information and instructions on how to work with children with special needs. These GON-teachers can work individually with the child but only on domains where the teacher in mainstream school is not trained for.

mmm STICORDI stands for Stimulating, Compensating, Relativating and Dispensating measures.

nnn The impossible value of 1080 minutes was put as a missing value. Therefore, there were 5 missing values.

Table 52: Frequencies of average time per day (in minutes) spent on helping with homework

Time	Frequency	Percent
0	14	16.9
5	2	2.4
10	4	4.8
12	1	1.2
15	1	1.2
20	5	6.0
25	1	1.2
30	25	30.1
45	6	7.2
60	15	18.1
75	1	1.2
80	2	2.4
90	2	2.4
120	3	3.6
210	1	1.2
Total	83	100.0
Missing	5	

Further questions investigate whether a general practitioner or a specialist has been contacted during the last two months because of the learning disorder of the child or a related problem ooo . Twelve respondents (14.5%) answer positively. Follow-up questions ask details: whether it was a general practitioner or a specialist, the reason(s) for the consultation and the number of consultations. The answers given are inconsistentppp. Eight contacted a general practitioner, but it seems that in only half of the cases, this was related to the learning disorder. Seven have contacted a specialist, probably in only 5 cases related to the learning disorder. Given these inconsistencies, we do not attribute costs to these interventions.

Parents want to be informed on the disorder of their child and therefore buy books related to the disorder, attend information sessions or consult professionals: 40.5% of the respondents (34 respondents) state they made costs during the previous year for this purpose. Unfortunately not all respondents effectively state the amount of those costsqqq. Mean costs (inclusive zeros) amount to €32. Non-zero costs vary between €2 and €900 with a median value of €25 (see Table 54). Costs of books are most frequently recorded (18 times).

On top of information costs, respondents cite that also additional school supplies/software are important cost items to include.

ooo There were 5 missing values.

ppp Respondents indicate they contacted a GP/specialist while they first indicated they did not have any consultation; or stated the reason was a viral infection, or a sports accident while only problems related to the learning disorder had to be recorded.

qqq 13 respondents do not mention the cost; 2 respondents record a cost while they first mentioned they did not have any costs.

Table 53: Frequencies of cost of information gathering during previous year

€	Frequency	Percent
.00	48	67.6
0.01 - 10.00	2	2.8
10.01 - 20.00	6	8.5
20.01 - 30.00	5	7.0
30.01 - 50.00	6	8.5
103.00	1	1.4
350.00	1	1.4
400.00	1	1.4
900.00	1	1.4
Total	71	100.0
Missing	17	

A high percentage of the respondents (38%) report changes in their or in their partner's working situationrrr. In more than 50% of the cases, the respondent started working fewer hours (17 respondents)sss. Twelve of them report the number of reduced working hours; it amounts to 10.3 hours on average with a median value of 8 hours. Partners less often change their working hours: only 2 did it. Overall, only 7 partners report a change in their working situationttt.

A high percentage of the respondents (41%, 34 respondents) report they made additional transportation costs because of the learning disabilities of their child during the last monthuuu. In 32 cases extra kilometres are made by car; in 3 cases with public transport. On average, 146.5 additional kilometres are driven by car and 13.7 by public transport (when extra transportations are made in the last month). The cost of this additional transport is calculated. A price of €0.2940 per kilometre by car and a price of €0.1 per kilometre for public transport were takenvvv. The resulting frequencies of the costs (inclusive zero costs) are in Table 54. Mean additional transportation costs amount to €16.9 per month; the median value of non-zero costs amounts to €26.17. Only 12.2% of respondents have costs higher than €50.

In addition to the costs of the transport itself, there is also the time spent during these transportations: on average more than two hours and a half per month. This is extremely large, given that 65% of the respondents report 0 additional time for transportations. The distribution is highly skewed to the right. The two largest values amount to 1640 and 1200 minutes per month; this is respectively about 1 hour and 40 minutes per day. Possible explanations for this outlier could be that the question is wrongly interpreted by the parents or they filled out the daily transport to special education (which takes in most cases a long drive in Belgium). The standard deviation (341.76) is twice the average. The resulting frequencies are presented in Table 55.

On top of transportation time, also other additional time input for the child (e.g. when waiting during therapy) could be reported. Additional time input was reported in 65 respondents (73.9%). The time input in these respondents varies from 5 to 7200 minutes per month.

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rrr There were 4 missing values.

sss There were 57 missing values.

ttt There were 53 missing values.

uuu There were 5 missing values.

vvv The official reimbursement for use of private car by public employees is used as a shadow price for private transport. Public transport costs for the user are very different according to the type of transport, the distance and type of payment; € 0.1 is taken as ad hoc value after checking some of the tariffs.

For the respondents reporting additional time, mean and median values are respectively 670 minutes and 360 minutes. It is unclear whether respondents really reported additional time input due to the disorder of their child. In any case these figures (see Table 56) show that time input is certainly important.

Table 54: Frequencies of transportation cost in past month

€	Frequency	Percent
.00	48	58.5
0.01 - 10.00	6	7.3
10.01 - 20.00	5	6.1
20.01- 30.00	7	8.5
30.01 - 50.00	6	7.3
50.01 - 80.00	6	7.3
80.01 - 100.00	3	3.7
188.16	1	1.2
Total	82	100.0
Missing	6	

Table 55: Frequencies of time (in minutes) of extra transportations

Time (in minutes)	Frequency	Percent
0	49	65.3
1- 120	4	5.3
121 - 240	10	13.3
241 - 360	2	2.7
361 - 480	2	2.7
481 -600	2	2.7
601 - 1000	3	4.0
1200	1	1.3
1640	2	2.7
Total	75	100.0
Missing	13	

Table 56: Frequencies of extra time spent on child in minutes

Time (in minutes)	Frequency	Percent
5 - 60	8	12.3
61 - 120	6	9.2
121 - 180	8	12.3
181 - 240	6	9.2
241 - 300	4	6.2
301 - 420	1	1.5
421 - 540	10	15.4
541 - 720	9	13.9
721 - 960	3	4.6
961 -1200	3	4.6
1350	1	1.5
1380	1	1.5
1440	1	1.5
1560	1	1.5
2360	1	1.5
6360	1	1.5
7200	1	1.5
Total	65	100.0
Missing	23	

5.3.7 A summary of total costs for the parents

We obtained good information on the patient cost of the treatment in the rehabilitation centre and reasonable values for patient costs for drugs, information and transportation but not on medical costs outside the rehabilitation centre. If all cost components[www] are added with exclusion of the latter unreliable cost items, a proximate total cost per month from the point of view of the patient is obtained. The results are summarized in Table 57. The mean patient cost per month amounts to € 32.2 and median costs are €14.5. Additional transportation costs are most important (about half of the total costs) followed by co-payments for the therapy in the rehabilitation centre (about one fourth of total costs). Information costs and drug costs are relatively unimportant. In comparison to the average monthly cost paid by the health insurance (€643) the patient' share is small. Also in absolute value, the total patient cost is not high and in general does not put a heavy financial burden on the parents. Moreover, 13% of the patients receive increased child allowances (see further), in which case society contributes even more in the extra costs for these children's learning problems. Opportunity costs seem much more important: parents invest additional time in their children, sometimes even reduce working time because of this.

A positive correlation between the total cost paid by the patient and household income was observed (Pearson correlation coefficient = 0.345, significant at the 0.01 level, two tailed). Mean costs are also higher for patients with 'abnormal' SDQ values (in comparison to those with normal values). A possible explanation could be that abnormal scores imply a larger need for care.

www Costs of information were divided by 12 to obtain a cost per month.

Table 57: Frequencies of total patient costs per month

€	Frequency	Percent
0	6	9.2
0.01 - 10.00	13	20.0
10.00 - 20.00	18	27.7
20.01 - 50.00	16	24.6
50.01 - 100.00	8	12.3
108.20	1	1.5
129.65	1	1.5
160.04	1	1.5
198.81	1	1.5
Total	65	100.0
Missing	23	

5.4 CONCLUSION

5.4.1 The questionnaire and the invoices

Creating a qualitative good questionnaire demands a process of continuous adjustments. By piloting and revising the questionnaire by several experts it underwent already many changes, but some growing pains still remained. In this chapter recommendations are formulated to improve the content and the use of this kind of questionnaires for future research.

Bearing in mind that filling in questionnaires takes time and energy from the parents, questionnaires should be shortened and should focus only on the essence. For example, the questions related to the amount and kinds of therapy in the rehabilitation centre were not filled out adequately. The number of missing observations increases as the questionnaire continues. Part of the information was more adequately retrieved from the invoices of the rehabilitation centres. Removing these questions from this part of the questionnaire would facilitate the work of the respondents. In addition to this, the rehabilitation centres can also serve as a source of information, for example by providing date of birth, sex, diagnosis, insurance status… and therefore increase the reliability of the gathered information while the number of items in the questionnaire will reduce. This can be suggested because the participating rehabilitation centres provided a lot of time and energy to fully cooperate in this study, making their contribution valuable for further research.

Next to the burden that parents experience in filling in the questionnaire, researchers experienced similar problems when analysing the questionnaire. The time of input is impressive (about 20 minutes per questionnaire and 20 minutes to control the data (10 minutes * 2 persons 1 reading the questionnaire, 1 controlling computer input)). The invoices take about 10 minutes per child for data input and 10 minutes for control. Searching to correct inconsistencies (for example general cost information: first there is a question asking whether or not costs are made and further question ask for more details. Sometimes respondents state they made no costs but further on fill in values and vice versa) and calculating variables (for example French invoices often do not mention number of lump sums) slow down the analyses. Sometimes it was even impossible to distinguish between a true 0 and missing information. In the future it should be omitted that parents can select multiple answers (for example the question how the professional situation changed: ask the respondent to indicate the most important change). Future research should also include extra time to contact the rehabilitation centres to verify for example missing invoices.

5.4.2 The results

In general, the cooperation with the rehabilitation centres and the response of the parents was good. Rehabilitation centres were able and willing to provide the necessary invoices and patient reports and respondents - with exception of the remarks in the previous paragraph - filled out the questionnaire.

5.4.2.1 Costs

Good information was gathered on the cost of the treatment in the rehabilitation centre and reasonable values for patient costs for drugs, information and transportation but not for medical costs outside the rehabilitation centre. Treatment costs in the rehabilitation centre are most important: they amount to €651 per month; €643 is reimbursed by the health insurance and €8 per month paid by the patient. Treatment outside the rehabilitation centre is relatively unimportant. A proximate total cost per month from the point of view of the patient is obtained (with exclusion of the unreliable cost items). The mean patient cost per month amounts to € 32.2 and median costs are € 14.5. Additional transportation costs followed by co-payments of the therapy in the rehabilitation centre are most important. Information costs and drug costs are relatively unimportant and in comparison to the costs paid by the health insurance (€ 643), the patient costs are small. Opportunity costs (e.g. parents helping with home work or reducing working time) seem the most important for parents. However, it is important to interpret these results cautiously, due to the small sample size.

There is not much information available in Belgium to compare these costs. In general the costs reimbursed by the health insurance are relatively large: the costs *per month* of treatment in the *rehabilitation* centre (€643) are higher than the *total health insurance costs* for an average child *per year* (which amounted to €590 for a 5-9 year old child and to €534 for a 10-14 year old child in 2006)[xxx]. A study performed in 2003 on the costs of children with ADHD revealed lower costs as well (De Ridder and De Graeve, 2006). In the ADHD study, the total yearly reimbursed medical cost amounted to about €1000 per child; reimbursed costs for physiotherapy, speech and language therapy, occupational therapy and psychotherapy amounted to €432 per year.

On the other hand, patient contributions in our study seem low: €8 per month for rehabilitation (1.2 % of the total cost) in comparison to €222 (34% of the total cost) for physiotherapy, speech and language therapy, occupational therapy and psychotherapy per year for children with ADHD).

It should be noted, that 13% of the children in the group of developmental disorders of scholastic skills, receive increased child allowances. This further compensates for the costs and inconveniences due to the child's problems.

Finally, it has to be mentioned that also teachers and the school environment pay a lot of special attention to this group of children: 30% of the parents reports that their child receives extra support at school.

5.4.2.2 Outcome

When studies investigate the gains of certain treatment methods the use of a control group receiving no or other treatment is recommended. Only when this is incorporated strong statements can be made about the evidence of a treatment. As in this research no control group was used, the only careful conclusions concern the gains made in the individual child.

The Strengths and Difficulties Questionnaire (SDQ) was administered to the parents. The total difficulties score is in the 'normal range' (a score between 0 and 13) for 59% of the children, in the 'borderline range' (a score between 14 and 16) for 12% of the children and in the 'abnormal range' (a score higher than 16) for 29% of the children.

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xxx Statistical information accessed on September 4, 2008 at http://www.riziv.fgov.be/information/nl/statistics/health/2007/pdf/statisticshealth2007all.pdf

As expected, the results from the SDQ showed that these children do not only experience problems concerning learning, 20% have also peer problems and 12% have also conduct problems. Children also show frequently higher scores on hyperactivity (40%) and emotional problems (38%).

When these gathered scores are compared with mean scores of the Dutch version of the SDQ by age 8-10 -the mean age of the sample- (see [297], it can be concluded that the sample shows more total difficulties (12.9) compared to the 'normal population' (7.8). When looking at the subscales, the sample showed more emotional symptoms (mean 3.8 in comparison with 2.4), conduct problems (mean 5.6 in comparison with 1.1), hyperactivity/inattention (mean 5.6 in comparison with 3.1), peer problems (mean 2.0 in comparison with 1.2) and prosocial behaviour (mean 8.0 in comparison with 8.8, but this is in the opposite direction). There is also an indication that SDQ-scores are higher and present more abnormal values in the French speaking rehabilitation centres. A mean value of the total SDQ-score of 12.4 and 25% abnormal values for the Dutch questionnaire versus an average of 15.6 and 50% abnormal values for the French questionnaire were obtained. Caution is necessary given the small number of participating French children; however, it is worthwhile to take these findings in consideration when outcome is investigated in the future.

Relying on the information gathered from the parents in the questionnaire concerning the changes of the behaviour of the child with respect to functioning at school, emotional and social functioning, all parents evaluated the evolution of the child in a positive way. This is especially the case for functioning at school, self reliance and confidence of the child.

Based on the reports of the patients in the rehabilitation centres, a great difference was perceived between the average gain and the minimum and maximum gain expressed in percentiles in the different domains (technical reading, reading comprehension, orthographic, mathematics and context rich mathematical problems). In addition to this, there was a small sample on which gains were based and there were a lot of missing data. Therefore, only a careful conclusion can be drawn that most of the children probably made gains on the abovementioned domains (based on the average gains).

However, to draw conclusions concerning the outcome of a therapy or a treatment based on reports of the rehabilitation centres, it is necessary that the rehabilitation centres evaluate twice the same domain. As both of these two crucial issues were lacking, it was impossible for the researchers to make a statement about the outcome based on the reports. When future research wants to incorporate reports to draw conclusions, the process of making reports should be revised. First of all, the tests used to measure outcome in the domains of reading, mathematical skills etc., should be more standardized. Currently, a RIZIV/INAMI working group is dealing with this subject. In this pilot-study, outcomes on the physiotherapy domain were not included, but since more than 50% of the children in the sample receives physiotherapy, it would be worthwhile to include this domain in future studies. Further, it is important not only to include measures on reading or mathematics but also on well-being of the child. The fact that a child experiences less fear of failure after therapy is also an important result of rehabilitation. This domain should be measured for all children, but it is even more important in children receiving psychotherapy in the centre (48% percent in the sample). The use of the SDQ proved to be a good measure for this. Although it was only filled out once in this research, it could also serve as a measure of the effects of therapy by filling out the questionnaire pre and post therapy. Research is also possible when it is based on the evaluation of the parents, although this is rather subjective information and it should be treated with care. Future research should not only include the parents, but if possible the whole environment (child, parents, therapists, teachers, friends…) should be taken into account when drawing conclusions about outcome.

Finally, it has already been mentioned that results are much more convincing when they are also available for a control group. Future research should preferably also provide information on a control group, e.g. children from a waiting list.

5.4.2.3 Linking the costs to the outcome

Although the response rate to the questionnaire was quite high (69%), the results are only illustrative. No general conclusions can be drawn because inconsistencies in the costs and outcome collected make the results quite unreliable. No further analyses were made linking the costs to the outcome scores.

5.4.2.4 Usefulness of further research/ data collection

Preferably one would like to compare the costs and the outcome of children receiving treatment in the rehabilitation centre with the costs and outcome generated by a control group of patients receiving no and/or mono-disciplinary private (speech, psychomotor…) therapy or a combination of different private therapies. It could then be evaluated whether treatment in a rehabilitation centre leads to improved outcome, and at what additional cost. The data requirements for such a comparison however, are great.

First, one needs information on the outcome of the child. The ultimate goal of rehabilitation therapy should be to improve the long-run development and functioning of the individual (e.g. success in the labour market, minimal criminal behaviour, development of good social relationships, good school results…). Evidence on such long-term effects requires a long-term follow-up and is not immediately feasible. In the meantime, more intermediate outcome measures, such as those used in the current study (changes in SDQ, evolution in specific scholastic skills) could be taken. One should at least evaluate the performance of the child before the start of the therapy, at the end of the therapy and preferably after a follow-up time of 6 or 12 months. Currently, this is not possible in the NOKPSY rehabilitation centres. Since such information is not readily available in a standardized way, it should be collected; this is done in a most reliable way by an independent expert.

Second, one needs information on the costs generated by the therapy. Costs covered by the health insurance could be obtained through the Intermutualistic Agency (IMA). For opportunity costs and non-covered services, a questionnaire as the one used in this study is necessary. Finally the groups of children in the different treatment settings should be similar (in terms of morbidity and social characteristics). This necessitates random allocation of the children over the treatments, or at least matched pairs in the different settings. Application of regression methods in a net benefit framework could be used to identify important subgroups and adjust for imperfect randomisation (Hoch, Briggs and Willan, 2002).

An extension of the data collection as in the pilot study (with the suggested improvements in methodology) has usefulness as well. It would give more reliable information on the costs and the outcomes of the children. Moreover a sufficiently large sample would make it possible to perform multivariate analyses (e.g. OLS or GLM) to estimate the relationship between costs and key socio-economic, demographic and clinical characteristics and between outcome and these characteristics in the case of treatment in a rehabilitation centre. It would then e.g. be able to verify whether symptom severity is positively associated with costs, or whether higher costs are associated with better outcome and greater service satisfaction. Without a control group (e.g. waiting list patients), it will however not be possible to judge the usefulness of the therapy as such.

Key points

- **This cost-outcome study should be seen as a pilot-study only**
- **Combining billing information with information obtained in a questionnaire gives a comprehensive view on public and private costs of children treated in a rehabilitation centre for learning disabilities**
- **For treatment in the rehabilitation centre alone, preliminary information on the basis of a small pilot sample (88 respondents) points to relatively high public costs (€643 per month) but small patient costs (€8 per month)**
- **In this pilot sample, the total mean costs for parents were €32 (median €14), mainly composed of transportation costs.**
- **On the other hand, parents seem to have considerable opportunity costs (e.g. time spent to transportation, working less hours because of the child); and the school environment also invests a lot in these children.**
- **Measuring outcome on the basis of the reports in the rehabilitation centre is more challenging. The process of making reports should be revised and more uniform outcome scales should be used. Measures on well-being should be included as well, to give a more comprehensive view of the outcome.**
- **Summarizing information on outcome is not evident given the small pilot sample and the data lacunae. A careful conclusion is that some gains in scholastic skills (0-11 percentiles for one year of therapy) are made. The clinical significance of this gain is difficult to interpret. Parents report that improved functioning, self reliance and confidence are obtained.**
- **Evaluation of the cost-effectiveness of treatment in a rehabilitation centre is feasible and desirable but necessitates an ambitious data collection: on costs and on outcome for a sample treated in the rehabilitation centre and a control group.**

6 GENERAL CONCLUSION

This study highlighted several aspects of the multidisciplinary care in NOKPSY rehabilitation centres. Several aspects were considered:

-Who appeals to these multidisciplinary centres?

-What is the scientific evidence for multidisciplinary therapy?

-Which in- and exclusion criteria can be used for the NOKPSY target groups, given the complex field of other caregivers for these groups?

-What can be said on current organisation and financing of multidisciplinary care for the NOK/PSY target groups?

6.1 NOK/PSY REHABILITATION: WHO APPEALS TO THE MULTIDISCIPLINARY SERVICES OF THESE CENTRES?

The sample comprised 63% (n=26) of all NOK rehabilitation centres and 57% (n=28) of all PSY rehabilitation centres that are a member of the 'Federatie van Centra voor Ambulante Revalidatie'/'Fédération des Centres de Réadaption Ambulatoire'. In total, 4907 patients (3658 in Dutch speaking rehabilitation centres and 1249 in French speaking centres) participated. Analyses of the received data showed us that 4338 (88.40%) of the participating children could be assigned to three clusters 'mental retardation', 'developmental disorders' and 'behavioural disorders'. More in detail the main NOK/PSY-target groups are: children with specific developmental disorders of scholastic skills, children with mild mental retardation, children with specific developmental disorders of speech and language, children with pervasive developmental disorders and children with hyperkinetic disorders.

Co-morbid and associated disorders appeared to be rather the rule than the exception (see 6.2.2.1 for discussion).

6.2 MULTIDISCIPLINARY THERAPY FOR THE NOKPSY TARGET GROUPS: SCIENTIFIC EVIDENCE OR NOT?

First of all, the aspect of scientific evidence (according to the rules of EBM) was considered. No studies were found concerning the effects and differences between mono- and multidisciplinary treatment and the number of disciplines necessary to provide evidence-based psychosocial treatments. Most studies were limited to a specific age range. Also, most studies were limited to main disorders (investigating psychosocial treatments within children with only one diagnosis) without taking co-morbidity into account, and no conclusions could be drawn for this aspect. Also, only little or no evidence was found on intensity or duration of psychosocial treatments. Nevertheless, some interesting therapeutic guidelines and general principles can be retained from the literature review, which are summarized in the concluding remarks at the end of chapter 3.

Notwithstanding the lack of scientific evidence, in all of the six Western-European countries, multidisciplinary therapy for the studied 4 main index disorders exists. It is standard in all countries for pervasive developmental disorders and for hyperkinetic disorders; and it is often, but not always, available for developmental disorders of scholastic skills and for developmental disorders of speech and language. However, it is not provided in the specific context of Belgian NOK/PSY-rehabilitation centres (recognised by the government) but in the context of the educational system, child psychiatry or paediatrics, or the private system. It is also important to know that in many countries, "multidisciplinary" means "two or more disciplines" (instead of three or more disciplines). In most countries, as in Belgium, both the health (and social) system, and the educational system, are in charge of financing (part of) the multidisciplinary therapy.

6.3 MULTIDISCIPLINARY THERAPY FOR THE NOKPSY TARGET GROUPS, WHICH INCLUSION AND EXCLUSION CRITERIA?

If multidisciplinary therapy is provided for the NOKPSY target groups, what should be inclusion and exclusion criteria?

To answer this question, it is important to start from a clear description of the target groups that can potentially apply for multidisciplinary NOKPSY rehabilitation.

6.3.1 The RIZIV/INAMI classification, ICD-10 and ICF: general principles

The WHO considers the ICF (International Classification of Functioning, Disability and Health) and the ICD-10 to be distinct but complementary classifications, and a *joint* use of both is advised in rehabilitation medicine. However, so far the ICF-domains are not yet (fully) linked to outcome assessment instruments, which would allow for defining clear "cut-off" points to decide on in- and exclusion criteria.

The RIZIV/INAMI codification system for the NOK/PSY target groups, and the ICD-10 were both intensively studied in this study. Both consider only qualitative elements to describe the NOK/PSY target groups "Pervasive developmental disorders" and "Hyperkinetic disorders". For the measurement of "conductive and sensorineural hearing disorders", internationally accepted standards and measurement systems are available. Both, they propose for disorders of speech/language or scholastic skills, to respect a functioning at or below the limits of 2 standard deviations, or at / below the 3rd percentile, as compared to the general level of cognitive functioning of the person.

However, in line with the ICF, and as described in the conclusions of chapter 5, it would be worthwhile to investigate the impact of the disorder(s) on daily life, i.e. well-being, and to make a 'swot'-analysis of the patient and his environment not only when considering inclusion, but also especially when considering outcome. Currently, a RIZIV/INAMI working group formulates an advice on the use of more uniform outcome scales and reconsiders which measurement instruments should be used in the context of reimbursement for some specific target groups of the NOK/PSY centres and of the speech therapists. It is clear that measurements that are scientifically validated for the target groups under consideration should be preferred.

6.3.2 NOK/PSY multidisciplinary rehabilitation: one element in the current landscape of care provision for the target groups

In the context of reimbursement, it is also important to distinct the target groups of the NOK/PSY multidisciplinary rehabilitation centres from the other care givers in the field of these target groups.

This is not an easy question.

Although many NOKPSY rehabilitation centres (in)formally work together with other caregivers in the field, no clear definition has been found during this study on the specific task rehabilitation centres have as compared to other care providers belonging to their network.

6.3.2.1 Co-morbidities and associated disorders in the NOK/PSY population: helpful in deciding to mono- versus multidisciplinary treatment?

There is a correspondence between the descriptions of some RIZIV/INAMI-groups in NOK/PSY conventions and the RIZIV/INAMI nomenclature of mainly speech therapists, e.g. for learning and speech-language problems (see Appendix to Chapter 1). This leads to discussions about which clients should be taken care of by one discipline, and which by several disciplines in a multi- (or inter-) disciplinary way. NOK/PSY centres are established to take care of a more complex population. This raises questions how 'complexity' should be defined and which criteria can be used in order to decide whether mono-disciplinary or multidisciplinary therapy is indicated.

These questions are not easy, and the literature review in this report taught that for the target groups 'Pervasive developmental disorders', 'Hyperkinetic disorders',

'Developmental disorders of Scholastic skills', and 'Developmental disorders of speech and language', no evidence is available on the subject "mono-disciplinary or multidisciplinary therapy".

One could argument, that the complexity of a certain developmental disorders is defined by its number of co-morbidities or associated disorders: e.g., it might be difficult to help a child with a learning disorder and a co-morbid developmental coordination disorder without the involvement of several different disciplines. The results of the ICD-10 encoding in the current study, confirm that a large percentage of NOK/PSY clients have co-morbidities and/or associated disorder.

However, the rule "the more co-morbidities or associated disorders, the more different disciplines necessary" is not necessarily true. First of all, it might be very difficult to provide any useful therapy at all for certain co-morbidities, so that even a case with one or more co-morbidities can be treated in a mono-disciplinary way. Second, certain diagnostic categories can be complex as well, even without co-morbidities. E.g. pervasive developmental disorders are by definition complex, "pervading" the person's whole functioning. This might be an indication for multidisciplinary therapy as such. Another example is the ICD-10 codification "mixed developmental disorders of scholastic skills" (64% of all participants within the main index disorder "developmental disorders of scholastic skills" in the database of this study). This might be an indication for multidisciplinary therapy even without comorbidities or associated disorders, although this cannot be proven by literature evidence since no studies on this subject are available. The finding that the amount of different therapies provided per patient in the NOK/PSY centres is not linked to the amount of co-morbidities and/or associated disorders (information from Dutch centres only), can also be an indication that there is no straight relationship between the number of co-morbidities and/or associated problems and the need for multidisciplinary help.

To study the 'mono- versus multidisciplinary treatment'-question, a general methodological remark is that the ICD-10 encoding performed by the NOK/PSY centres' professionals in the data sample of the current study, so far has not been performed e.g. by speech therapists involved in mono-disciplinary treatment of possibly the same diagnostic groups. Hence, it is not known whether the patients these therapists deal with have less co-morbidities/associated disorders or not. Another methodological remark is that a verification of the results of the population sample through an independent encoding by a researcher of a random sample should be performed, because data have only been processed after termination of the registration period. However in this study the post hoc random sample verification (see methodology to Chapter 2) points out that the information provided by the centres revealed a reasonable correspondence to the registered ICD-10 codes.

In conclusion, although it seems reasonable that for some disorders co-morbidity is an indication for multidisciplinary treatment, (e.g. non-mixed learning disorders i.e. learning disorders not involving several learning domains), whereas others are complex as such (e.g., pervasive developmental disorders), it remains to be proven for which indications mono-disciplinary respectively multidisciplinary therapy is indicated to treat developmental disorders, and for which indications the presence of certain co-morbidities (and/or associated disorders) implicates a switch from mono- to multidisciplinary therapy. The registration of co-morbid and associated disorders results in a more accurate picture of the patient's problems, but it leads not to a better decision making concerning mono- or multidisciplinary treatment. Therefore a solid investigation of the impact of the disorder(s) on daily life and a 'swot'-analysis of the patient and his environment is needed (as well as a better knowledge of the effectiveness of the provided therapies). Last but not least, the discussion "mono versus multi" is only a discussion on a very little part of the existing care provision for children (or adults) with developmental disorders. Other partners in this field are (special) education, supporting care at home, residential care, and others. Ideally, the whole field of care should be taken into account to organise "individually tailored" care for everyone who needs it. In Belgium, this implies a difficult discussion between many different departments, regions and governments.

6.3.2.2 *ICD-codifications instead of RIZIV/INAMI codifications to decide on reimbursement: an added value?*

The RIZV/INAMI codifications are based on ICD-10, and there is a large overlap in both systems as to the patient categories taken care of in NOKPSY centres, e.g. the six most important ICD-10 main index disorders have an equivalent in the RIZIV/INAMI convention system. However, there are also some important differences in groups and patient classifications. The most important difference relates to the category "Borderline intellectual functioning" in the RIZIV/INAMI conventions (TIQ range 70-84), which in ICD-10 belongs to the category 'other and unspecified symptoms and signs involving cognitive functions and awareness…(R41.8)' and is not considered as a disorder as such.

Whereas 22.4 % of the (Dutch speaking) patients was ICD-10-codified as R41.8, a very large part of patients with the ICD-10 codification 'Developmental disorders of speech and language' and 'Developmental disorders of Scholastic skills' is codified as 'Borderline intellectual functioning' (25.8 to 61.4%). This category contains also many patients codified according to ICD-10 as having 'Mental retardation', 'Hyperkinetic disorders' and 'Pervasive developmental disorders' (11.6 to 25%).

Many reasons can possibly explain the phenomenon of mismatch between ICD-10 classification and RIZIV/INAMI codification, which becomes apparent not only in the case of the RIZIV/INAMI code "Borderline intellectual functioning", but also in the case of "Mild mental retardation", which is often involved in mismatch too (see chapter 2.9.3.3 B). One explanation might be an "upgrading" or "optimalization" because of reimbursement advantages; e.g. the RIZIV/INAMI code "Borderline intellectual functioning" allows for 4 years of reimbursement and the RIZIV/INAMI code "Mild mental retardation" for 6 years of reimbursement whereas e.g. the RIZIV/INAMI code 'Developmental disorders of Scholastic skills' only accounts for 2 years.

It is advised that the RIZIV/INAMI should reconsider the criteria for reimbursement allocation, in order to minimize the possibilities of misclassification because of reimbursement advantages. This is most urgent for the RIZIV/INAMI category "Borderline intellectual functioning", which in the database of this study overlapped with other categories to a very large extent. The process of adaptation of reimbursement allocation might be inspired by the ICD-10 classification. Whereas in the ICD-10 classification persons with "Borderline intellectual functioning" can be classified as having e.g. 'Developmental disorders of Scholastic skills' or 'Developmental disorders of speech and language', it has the drawback that the ICD-10 codes 'Developmental disorders of Scholastic skills' and 'Developmental disorders of speech and language' include a functioning at or below the level of the 3rd percentile *for the given IQ*. One should remain cautious that it does not become more difficult for persons in the RIZIV/INAMI category "Borderline intellectual functioning" to obtain reimbursement, than it is for persons in the IQ-range above 85.

Practically speaking, an option could also be to impose the registration of ICD-10 index disorder, comorbidities and associated disorders in the report that has to be sent to the medical advisers in order to obtain approval for reimbursement.

Last but not least, ideally other care providers for the NOK/PSY target groups should use the same codification system, in order to obtain a more complete picture of all aspects of the care for these persons.

6.4 ORGANISATION AND FINANCING OF MULTIDISCIPLINARY CARE FOR THE NOKPSY TARGET GROUP.

6.4.1 Regional distribution of NOKPSY centres

One of the main conclusions from chapter 1 is that the NOKPSY rehabilitation centres as well as the yearly per capita NOKPSY budget are spread unequally throughout Belgium. This is not only true on the level of the regions, but also on the level of the provinces within one region. E.g. the per capita budget is largest in Flanders, followed by Brussels, whereas the per capita budget in Walloon is only half the Flemish budget. A possible explanation for this finding is the moratorium on the development of new rehabilitation centres. Because their development was left to free initiatives, the distribution of centres resembles the situation before this moratorium. Another assumption is that there is a greater amount of other types of services (private speech therapists, special education with or without (semi-) boarding school, centres for mental health) in regions with less rehabilitation centres. This seems not to be valid. However, no complete conclusions can be drawn as the contribution of some other care providers for the involved target groups could not be included (child psychiatrists, educational support in mainstream schools…).

A plea for a more equal regional distribution of the centres, starting from a clearly outlined planning, has been formulated by the RIZIV/INAMI College of medical directors (College van geneesheren-directeurs/Collège de Médecins Directeurs) and the Council for advice on rehabilitation (Raad voor advies inzake revalidatie/ Conseil consultatif de la rééducation fonctionnelle) *('Verslag over de stand van de revalidatiegeneeskunde in België', 2004)*.

Ideally, the planning should start from prevalence numbers for the persons with the index disorders and a severity degree corresponding to the cut-off points as to degree of severity. However, such numbers are not available, and will be very difficult to obtain due to the many other care givers involved for the same target groups, some of which belong to other governmental departments or are financed on the regional and not the federal level. Probably currently the most practical approach is to start from comparing yearly per capita NOK/PSY budgets per province, as was done in chapter 1 of this study.

6.4.2 Outcomes and costs of NOKPSY rehabilitation centres

Cost-effectiveness of certain treatments becomes an issue, also in rehabilitation medicine. A pilot study has been conducted to evaluate the feasability for one of the NOKPSY target groups, namely developmental disorders of scholastic skills.

Measuring outcome evolution based on the reports in the rehabilitation centres is possible but nevertheless hampered by methodological difficulties, especially the need for more uniform outcome measurements, and preferably measurements including all ICF domains. Also, follow-up of the child (which is not possible in the current conventions) should allow for evaluation whether gains are retained after closing of the therapy.

Taken this into account, a careful conclusion from this small pilot sample is that some gains in scholastic skills were made (0-11 percentiles for one year of therapy), although the clinical significance of this gain is difficult to interpret. Parents report an improved functioning, self reliance and self confidence.

Concerning the costs, the children with a developmental disorder of scholastic skills in the small pilot study don't follow other therapies that are reimbursable by the RIZIV/INAMI; but parents as well as the school environment spend a lot of extra time to them. As such, parents seem to have a lot of opportunity costs (e.g. transportation costs, working less hours because of the child etc.).

The financial burden is to a large degree paid by society: the public costs (RIZIV/INAMI) for the rehabilitation treatment are €643 per month; the total median respectively mean costs for the parents are €14 respectively €32 per month. When compared roughly to the average RIZIV/INAMI cost per child, or to the RIZIV/INAMI reimbursement and the out-of-pocket payment for another developmental disorder in the Belgian context (ADHD, see De Ridder et al. 2006), the outcome in this study seems to be favourable. However, a more in-depth study is necessary before drawing definitive conclusions.

The national RIZIV/INAMI budget for the NOKPSY centres slightly declined as compared to the total RIZIV/INAMI budget between 1999 and 2007. As compared to the total RIZIV/INAMI rehabilitation budget, NOKPSY centres went down from more than 30% (1997-1998) and 28.5% (1999) to 20.5% in 2007.

In the six countries studied, the departments responsible for the funding are both the educational and the health department. Sometimes, the educational department is almost fully in charge of the 4 target groups under this study. Differences exist between the categories 'Specific developmental disorders of scholastic skills' or 'Specific developmental disorders of speech and language' on the one hand; and 'Pervasive developmental disorders' or 'Hyperkinetic disorders' on the other hand. The latter fall more often under the responsibility of the health department. In some countries the parents pay nothing for the multidisciplinary therapy.

6.4.3 Differences between NOK and PSY- and between French and Dutch speaking centres?

As to the difference between NOK and PSY centres, the two most important main index disorders, 'Mild mental retardation' and 'Developmental disorders of Scholastic skills', belong to the three most important main index disorders in NOK as well as in PSY; but 'Mild mental retardation' is more common in PSY (14% NOK, 22% PSY) whereas 'Developmental disorders of Scholastic skills' is more common in NOK (24% NOK, 11% PSY). Further, 'Developmental disorders of speech and language' belongs to the three most important main index disorders in NOK (16%), whereas 'Pervasive developmental disorders' belongs to the three most important main index disorders in PSY (15%). This confirms the differences in patient population between NOK and PSY centres. The five most important main index disorders in NOK respectively PSY centres, amount to 75% respectively 69%, when taken into account that 'Conductive and sensorineural hearing loss' cannot be treated in PSY centres. In other words, overall differences are not very large (see Table 22 in Chapter 2).

With the remark that the French NOK centres might not be fully representative, there are to mention some differences between the diagnostic codifications in the Dutch and the French speaking rehabilitation centres. The six most prevalent main index disorders (see Table 17) account for 83.9% of the main index disorders in Dutch speaking centres, and only for 59.7% in French speaking centres. The most striking example is the diagnosis 'Developmental disorders of Scholastic skills', which is frequent in Dutch centres (21.8% of all main index disorders) but less in French centres (6.1%). Next to the six most important index disorders for all centres together, the most frequent index disorders in French speaking centres are 'Moderate mental retardation' (7.2%), 'Mixed specific developmental disorders' (4.6%), 'Disorders of social functioning' (4.1%) and 'Cerebral palsy' (3.4%).

When comparing main index disorders for Dutch and French NOK respectively PSY centres (see Appendix to Chapter 2), the numbers of participants in one diagnostic category (especially in the French centres) became too small to judge on differences. Moreover, the database sample might not be fully representative for the French NOK centres. On the other hand, when comparing Dutch and French PSY centres within the RIZIV/INAMI codifications, the difference for 'Learning disorders' could be confirmed (13% respectively 0.6%), but also 'Hyperkinetic disorders' appeared to be more frequent in Dutch PSY centres (9.7% respectively 1.4%). 'Mental retardation' appeared to be more frequent in French PSY centres (34% respectively 54%).

Why the main index diagnostic categories are different in Dutch and French speaking centres, is not clear. Several hypotheses can be raised. The differences might be due to differences in medical schools between the two languages. It can also be that the patient population that presents to the French NOK/PSY centres is different from the Dutch patient population, because prevalence rates of certain disorders are different, or because other services that provide care for the same patient population (e.g. special education) are less prevalent or further away, so that parents prefer more nearby services.

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KCE reports

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