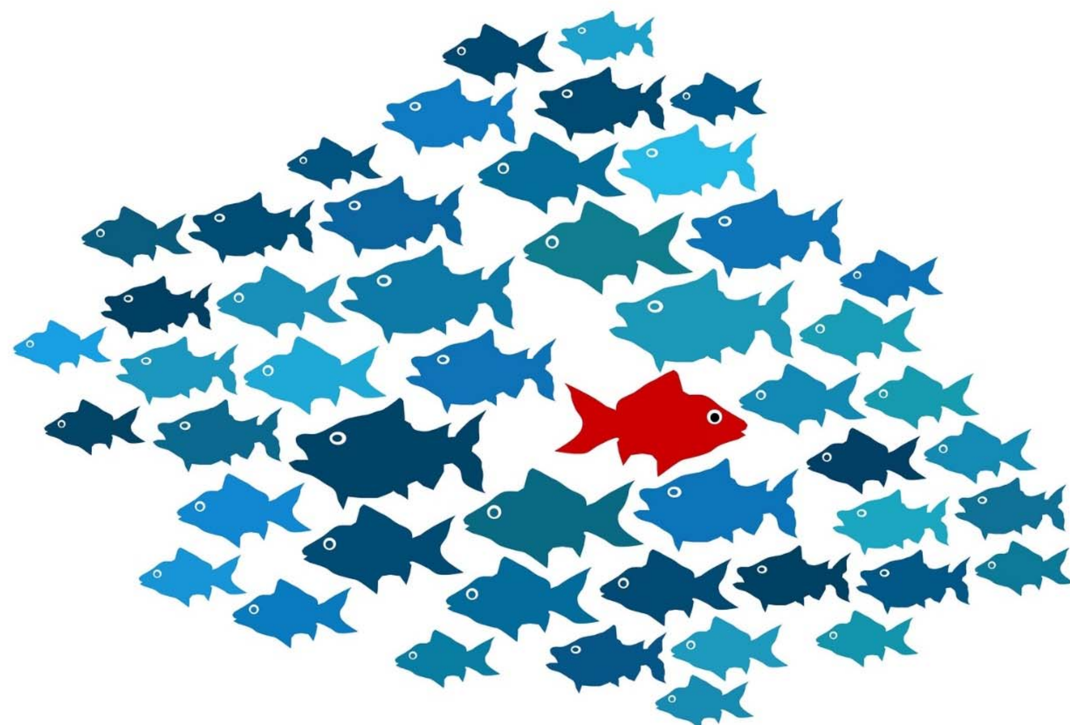
KCE REPORT 233Cs

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

EXECUTIVE SUMMARY

MANAGEMENT OF AUTISM IN CHILDREN AND YOUNG PEOPLE: A GOOD CLINICAL PRACTICE GUIDELINE



2014

www.kce.fgov.be

.be

Belgian Health Care Knowledge Centre

The Belgian Health Care Knowledge Centre (KCE) is an organization of public interest, created on the 24th of December 2002 under the supervision of the Minister of Public Health and Social Affairs. KCE is in charge of conducting studies that support the political decision making on health care and health insurance.

Executive Board

	Actual Members	*Substitute Members*
President	Pierre Gillet	
CEO - National Institute for Health and Disability Insurance (vice president)	Jo De Cock	Benoît Collin
President of the Federal Public Service Health, Food Chain Safety and Environment (vice president)	Dirk Cuypers	Christiaan Decoster
President of the Federal Public Service Social Security (vice president)	Frank Van Massenhove	Jan Bertels
General Administrator of the Federal Agency for Medicines and Health Products	Xavier De Cuyper	Greet Musch
Representatives of the Minister of Public Health	Bernard Lange	Brieuc Van Damme
	Bernard Vercruysse	Annick Poncé
Representatives of the Minister of Social Affairs	Lambert Stamatakis	Claudio Colantoni
	Ri De Ridder	Koen Vandewoude
Representatives of the Council of Ministers	Jean-Noël Godin	Philippe Henry de Generet
	Daniel Devos	Wilfried Den Tandt
Intermutualistic Agency	Michiel Callens	Frank De Smet
	Patrick Verertbruggen	Yolande Husden
	Xavier Brenez	Geert Messiaen
Professional Organisations - representatives of physicians	Marc Moens	Roland Lemye
	Jean-Pierre Baeyens	Rita Cuypers
Professional Organisations - representatives of nurses	Michel Foulon	Ludo Meyers
	Myriam Hubinon	Olivier Thonon
Hospital Federations	Johan Pauwels	Katrien Kesteloot
	Jean-Claude Praet	Pierre Smiets
Social Partners	Rita Thys	Catherine Rutten
	Paul Palsterman	Celien Van Moerkerke
House of Representatives	Lieve Wierinck	

Control

Government commissioner	Steven Sterckx

Management

General director	Raf Mertens
Deputy general director	Christian Léonard
Program Management	Kristel De Gauquier Dominique Paulus

Contact

Belgian Health Care Knowledge Centre (KCE)
Doorbuilding (10th Floor)
Boulevard du Jardin Botanique, 55
B-1000 Brussels
Belgium

T +32 [0]2 287 33 88
F +32 [0]2 287 33 85
info@kce.fgov.be
http://www.kce.fgov.be

KCE REPORT 233Cs
GOOD CLINICAL PRACTICE

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

SUMMARY

MANAGEMENT OF AUTISM IN CHILDREN AND YOUNG PEOPLE: A GOOD CLINICAL PRACTICE GUIDELINE

GENEVIÈVE VEEREMAN, KIRSTEN HOLDT HENNINGSEN, MARIJKE EYSSEN, NADIA BENAHMED, WENDY CHRISTIAENS, MARIE-HÉLÈNE BOUCHEZ, ANN DE ROECK, NICOLAS DECONINCK, GABY DE LIGNE, GRIET DEWITTE, TINE GHEYSEN, MARYSE HENDRIX, CLAIRE KAGAN, GHISLAIN MAGEROTTE, MARLEEN MOONEN, HERBERT ROEYERS, SARAH SCHELSTRAETE, MARIE-VINCIANE SONCARRIEU, JEAN STEYAERT, FLAVIO TOLFO, GÉRALDINE VRANCKEN, ERIC WILLAYE, ANNE WINTGENS, SARA WOUTERS, JAN CROONENBERGHS.

2014 www.kce.fgov.be

.be

COLOPHON

Title:	Management of autism in children and young people: a good clinical practice guideline – Summary
Authors:	Geneviève Veereman (KCE), Kirsten Holdt Henningsen (KCE), Marijke Eyssen (KCE), Nadia Benahmed (KCE), Wendy Christiaens (KCE), Marie-Hélène Bouchez (CRA Mons; Fondation SUSA asbl), Ann De Roeck (De Vijver), Nicolas Deconinck (CRA HUDERF, ULB), Gaby De ligne (RCA UZ Brussel), Griet Dewitte (COS Gent), Tine Gheysen (vrije CLB-koepel vzw), Maryse Hendrix (AWIPH), Claire Kagan (PMS Fédération Wallonie Bruxelles), Ghislain Magerotte (Université de Mons; Fondation SUSA asbl), Marleen Moonen (RCA UZ Brussel), Herbert Roeyers (RCA Gent; Ugent), Sarah Schelstraete (VVA), Marie-Vinciane Soncarrieu (CRA HUDERF), Jean Steyaert (ECA Leuven; UZ Leuven; KULeuven), Flavio Tolfo (Inforautisme asbl; GAMP), Géraldine Vrancken (CRAL), Eric Willaye (Fondation SUSA asbl), Anne Wintgens (CRA; Cliniques universitaires Saint-Luc; UCL), Sara Wouters (RCA; UZ Brussel), Jan Croonenberghs (ZNA UKJA; RCA Antwerpen; UA)
Reviewers:	Hans Van Brabandt (KCE), Anja Desomer (KCE)
Editor synthesis:	Karin Rondia (KCE)
External experts:	Pascale Grevesse (Fondation SUSA asbl), Vincent Ramaekers (CRAL; CHU de Liège; Ulg), An Thijs (VVKBuO; VSKO)
Stakeholders:	Alec Aeby (BVKN–SBNP; Hôpital Erasme; ULB); Cinzia Agoni (Inforautisme asbl), Krista Ceustermans (VVL), Sofie Crommen (VVK), Bruno Darras (BFP–FBP; Centre Henri Wallon), Jennifer De Smet (VVPT; UPC KULeuven), Olivier Fourez (INAMI – RIZIV), Sylvie Gérard (CSS–HGR), Freddy Hanot (APEPA asbl), Fabienne Hody (ACSEH; ACJB; Centre de jour Grandir, Bruxelles), Mireille Johnen (PHARE; COCOF), Abdelkhalak Kajjal (Les briques du GAMP), Philippe Kinoo (SBFPDAEA; Cliniques universitaires Saint-Luc), Jo Lebeer (Domus Medica; UA), Reinhilde Lenaerts (VE vzw), Koen Lowet (BFP-FBP; Multifunctioneel centrum Behtanië), Christelle Maillart (UPLF; Ulg), Alain Malchair (SBFPDAEA; CHU de Liège; Ulg), Hilde Meganck (GO! Onderwijs), Ilse Noens (KULeuven), Etienne Oleffe (AFrAHM), Hilde Olivié (Stijn vzw; COS UZ Leuven), Els Ortibus (BVKN–SBNP; COS UZ Leuven; KU Leuven), Francisca Schiltmans (VVA), Eric Schoentjes (VVK), Anne Taymans (UPBPF), Francis Turine (FSPST), Julie Vandemeulebroecke (VVPMT), Philippe Van Vlaenderen (SSMG), Peter Vermeulen (Autisme Centraal), Marek Wojciechowski (BVK–SBP; UZA), Geert Devos (OVSG; Autisme Heynsdaele), Katelijne Van Hoeck (CLB GO! Onderwijs)
External Assessors:	Philippe Evrard (Université Paris Diderot Paris 7, France; Service de neurologie pédiatrique et des maladies métaboliques, Hôpital universitaire Robert Debré, Assistance Publique - Hôpitaux de Paris, France), Jonathan Green (University of Manchester, United Kingdom ; Honorary Consultant Child and Adolescent Psychiatrist, Central Manchester and Manchester Children’s Hospitals University NHS Trust and Manchester Biomedical Research Centre, United Kingdom),

External validators:	Trudy Bekkering (CEBAM), Hans Hellemans (ZNA UKJA; RCA Antwerpen), Patrik Vankrunkelsven (Academisch Centrum voor Huisartsgeneeskunde KU Leuven; CEBAM)
Affiliations:	All affiliations of the authors, external experts, stakeholders, external assessors and external validators are written in full and with more explication in Appendix 1 of the Supplement
Other reported interests:	Membership of a stakeholder group on which the results of this report could have an impact: *Anne Wintgens (*Centre de Référence des Troubles du Spectre Autistique des Cliniques Universitaires Saint-Luc), Marie-Vinciane Soncarrieu (Université Libre de Bruxelles; Faculté de Médecine), Nicolas Deconinck (ULB), Géraldine Vrancken (ASBL Participate Autisme) Holder of intellectual property (patent, product developer, copyrights, trademarks, etc.): Peter Vermeulen (Author of books about autism) Fees or other compensation for writing a publication or participating in its development: Peter Vermeulen (Author of books about autism), Griet Dewitte (author of books), Eric Willaye (Conseil Supérieur de la Santé) A grant, fees or funds for a member of staff or another form of compensation for the execution of research: Anne Wintgens (Demande en cours pour la recherche 5), Nicolas Deconinck (financing project Kids Foundation), Ilse Noens (promotor/PI PhD students investigating autism), Marie-Vinciane Soncarrieu (Kids Foundation) Consultancy or employment for a company, an association or an organisation that may gain or lose financially due to the results of this report: Bruno Darras (Centre Henri Wallon), Peter Vermeulen (Autisme Centraal), Fabienne Hody (Centre de jour « Grandir »), Jan Croonenberghs (ZNA ziekenhuis), Jean Steyaert (Reference centre Autism), Krista Ceustermans (speech therapist rehabilitation centre Het Roer), Eric Willaye (Fondation SUSA asbl), Freddy Hanot (Autisme Europe asbl), Payments to speak, training remuneration, subsidised travel or payment for participation at a conference: Peter Vermeulen (Autisme Centraal), Nicolas Deconinck (presentation about early signs of autism), Jean Steyaert (post degree KUL 'therapy for autism and mental disability), Marek Wojciechowski, Griet Dewitte, Jonathan Green Presidency or accountable function within an institution, association, department or other entity on which the results of this report could have an impact: Bruno Darras (Centre Henri Wallon), Els Ortibus (Directeur bij Centrum voor Ontwikkelingsstoornissen), Alain Malchair (Directeur Thérapeutique du Centre de Santé Mentale Universitaire de Liège), Peter Vermeulen (CO-CEO Autisme Centraal), Francisca Schiltmans (Vlaamse Vereniging Autisme), Sofie Crommen (president VVK), Philippe Kinoo (Société Belge Francophone de Psychiatrie et Disciplines Associées de l'Enfant et de l'Adolescent), Fabienne Hody (Responsable « Grandir »), Anne Taymans (Association Professionnelle des Psychomotriciens), Anne Wintgens (Responsable reference centre autistic spectrum troubles of the Cliniques Universitaires Saint-Luc), Nicolas Deconinck (Co-CEO of the reference centre Autism of the ULB), Géraldine Vrancken (ASBL Participate Austisme), Éric Willaye (AWIPH ; INAMI), Cinzia Agoni (Administrateur Inforautisme ASBL et de Les Briques du Gamp ASBL), Flavio Tolfo (Administrator Inforautisme, Fondation SUSA, Coupole Bruxelloise de l'Austisme. Président Les Briques du GAMP ASBL), Ghislain Magerotte (President of honour of the Fondation SUSA), Jan Croonenberghs (ZNA ziekenhuis), Jean Steyaert (coordinator reference

centre Autism UZ Leuven), Marie-Vinciane Soncarrieu (responsable autism centre), Eric Schoentjes (VVK), Herbert Roeyers (chairman Board Meeting support at home service; board member COS), Sara Wouters (coordinator reference centre Autism Brussels), Marie-Hélène Bouchez (president Fondation SUSA), Freddy Hanot (president APEPA asbl ; administrator Autisme Europe aisbl ; administrator Participate Autisme asbl)

Participation in scientific or experimental research as an initiator, principal investigator or researcher: Alain Malchair (Collaboration with CRAL), Anne Wintgens (study on the emotional regulation in autism and exchange and development therapies), Marie-Vinciane Soncarrieu (co-investigator study Memantine phaze III study 2013-2014), Nicolas Deconinck (étude Memantine (PI), phaze III study 2013-2014), Jan Croonenberghs (European grant IMI), Jean Steyaert (research at Leuven Autisme Research), Ilse Noens (PI effectiveness studiese on people with autism), Marek Wojciechowski (clinical researchprojects about Down syndroom), Sara Wouters (PI study 'Medicatie…), Jonathan Green (lead research into interventions for autism)

Other possible interests that could lead to a potential or actual conflict of interest: Ghislain Magerotte (Member of the Conseil Scientifique du Fonds de Soutien M.M. Delacroix)

Layout: Ine Verhulst

Disclaimer:

- **The external experts and stakeholders were consulted about a (preliminary) version of the scientific report. Their comments were discussed during meetings. They did not co-author the scientific report and did not necessarily agree with its content.**
- **Subsequently, a (final) version was submitted to the assessors and the validators. The validation of the report results from a consensus or a voting process between the assesoosrs and the validators. The assessors and validators did not co-author the scientific report and did not necessarily all three agree with its content.**
- **Finally, this report has been approved by common assent by the Executive Board.**
- **Only the KCE is responsible for errors or omissions that could persist. The policy recommendations are also under the full responsibility of the KCE.**

Publication date: 4 November 2014

Domain: Good Clinical Practice (GCP)

MeSH: Child Development Disorders, Pervasive ; Child ; Adolescent ; Therapeutics ; Psychotherapy

NLM Classification: WS 350.8.P4

Language: English

Format: Adobe® PDF™ (A4)

Legal depot: D/2014/10.273/86

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

How to refer to this document? Veereman G, Holdt Henningsen K, Eyssen M, Benahmed N, Christiaens W, Bouchez M-H, De Roeck A, Deconinck N, De ligne G, Dewitte G, Gheysen T, Hendrix M, Kagan C, Magerotte G, Moonen M, Roeyers H, Schelstraete S, Soncarrieu M-V, Steyaert J, Tolfo F, Vrancken G, Willaye E, Wintgens A, Wouters S, Croonenberghs J. Management of autism in children and young people: a good clinical practice guideline – Summary. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2014. KCE Reports 233Cs. D/2014/10.273/86.

FOREWORD

Autism is a so-called neurodevelopmental disorder. In other words, it is a disorder imprinted in the structural development of the brain, and for which, as a consequence, there can be no cure. To all those involved with children or adolescents the challenge is rather to find the best possible options to foster optimal realization of the aptitudes they have, and to avoid or control challenging behaviour or associated problems. These best options or therapies for these children and adolescents are the subject our report.

The task assigned by the Minister of Health to assess the management of autism in children and adolescents was a considerable challenge for the Belgian Health Care Knowledge Centre. In mental healthcare, high-quality clinical studies are scarce anyway, and therefore it was clear from the beginning that applying a strictly *evidence-based* methodology would be difficult. In addition, there is a heated debate amongst professionals dealing with children, adolescents (and adults) with autism spectrum disorder: those advocating a biological and behavioural approach oppose those who believe in a more psychosocial approach. Whilst the only relevant question for the patient and his parents is to know: “What does actually work?”

This is the question that we need to start answering. We build on any reliable scientific study results available in the literature for this field. This included the valuable work by our colleagues at the British National Institute for Health and Care Excellence (NICE) and the French Haute Autorité de Santé (HAS), which greatly inspired our approach. However, the yield from the scientific literature was very disappointing for many aspects of the problem. In such case, we must rely on the expertise and experience of the care providers – with diverse backgrounds – in our working group. The recommendations that have been formulated are based on a broad consensus among the consulted experts, taking into account the current Belgian context. A consensus substantiated by - and never contradicting - the scientific results.

Perhaps the negative results are the most important results of our work: the list of interventions and treatments that one should rather not waste time and money on, due to lack of proven efficacy. Hopefully this will contribute to reducing false hope and futile costs and efforts for the (parents of) patients, who often desperately search for help and solutions. In addition, there are fortunately a great number of recommendations for therapies and initiatives that are worth the effort, both for patients and their parents, for the professional care providers and for policy-makers. We hope that our numerous recommendations will provide an impulse in the right direction - over the entire spectrum - and we sincerely thank the many experts and stakeholders who devoted so much of their energy into this collaborative effort.

Christian LÉONARD
Assistant Chief Executive Officer

Raf MERTENS
Chief Executive Officer

■ TABLE OF CONTENTS

■ **FOREWORD** 1
■ **TABLE OF CONTENTS** 2
■ **EXECUTIVE SUMMARY** 3
1. **INTRODUCTION** 3
2. **OBJECTIVES AND SCOPE OF THIS GUIDELINE** 4
2.1. SCOPE 4
2.2. RESEARCH QUESTIONS 4
3. **METHODS** 4
3.1. SYSTEMATIC REVIEW OF THE LITERATURE 4
3.2. FORMULATION OF RECOMMENDATIONS 5
4. **CLINICAL RECOMMENDATIONS** 5
5. **DISCUSSION** 8
5.1. BEST AVAILABLE EVIDENCE 8
5.2. HOW TO USE THIS GUIDELINE 8
■ **REFERENCES** 9

■ EXECUTIVE SUMMARY

1. INTRODUCTION

According to DSM-5 (and the proposed ICD-11 criteria) children and adolescents, who are diagnosed with autism spectrum disorder (ASD) share two sets of characteristics:

- Persistent deficits in social communication and social interaction across multiple contexts.
- Repetitive behaviour which may be expressed by restricted, obsessive or repetitive activities reflecting difficulties adapting to change and unusually narrow interest, as well as sensory sensitivities [1].

It is usually impossible to determine one definite cause of autism in a child. Genetics are known to play an important role. ASD is considered a neuro-developmental disorder and although treatment can improve certain behavioural aspects, the disorder cannot be “cured”. With the development of behavioural therapies in Anglo-Saxon countries there has been a shift in treatment approaches. Therefore, the request was introduced to KCE for an evidence based guideline for the treatment of autism in children and adolescents. We were faced with several challenges such as the lack of clinical studies demonstrating evidence and the differences in organization of care within the country, leading to a wide scope of expectations.

2. OBJECTIVES AND SCOPE OF THIS GUIDELINE

2.1. Scope

The aim of this guideline is to offer an overview of the current evidence on the management of autism in children and adolescents and to formulate recommendations. The target users are parents and professionals caring for children and adolescents with autism at home, in medical settings and in institutions.

The GDG focused on two questions:

1. What is the current scientific evidence for psychosocial interventions, educational, biomedical and pharmacological treatments for children and young people with ASD, with or without a double diagnosis ASD, intellectual disability or other associated features?
2. What is good clinical practice management for children and young people with ASD and their families?

2.2. Research questions

The final selection of research questions was made during an initial scoping meeting at KCE on October 8th, 2013. These questions were addressed by the recommendations.

3. METHODS

3.1. Systematic review of the literature

A search for clinical guidelines was carried out in several databases and institutional websites (OVID Medline, the National Guideline Clearing House (http://www.guideline.gov/) and Guidelines International Network (http://www.g-i-n.net/ and Belgian websites). The search covered the period from 1 January 2008 to 24 June 2013. Two independent researchers performed the selection and the quality appraisal of the guidelines. We finally retained two guidelines: a guideline elaborated by the Haute Autorité de la Santé (HAS) (2012)[2] and the most recent guideline published by the National Institute for Health and Care Excellence (NICE) in UK.[1] The information obtained from these two guidelines was used following a structured and formal methodology that was developed by the ADAPTE group.[3] It was decided to prioritize and follow the structure of the NICE guideline because of its comprehensiveness and superior score on AGREE II. The evidence was therefore presented for six domains:

Domain 1: Experience of care and the organisation and delivery of care

Domain 2: Interventions aimed at core features of autism

Domain 3: Interventions aimed at behaviour that challenges

Domain 4: Intervention aimed at associated features of autism and co-existing conditions

Domain 5: Interventions aimed at improving the impact of the family

Domain 6: Adverse events associated with interventions

3.2. Formulation of recommendations

Evidence or consensus statements from both guidelines were summarized in tables per outcome and per domain. Based on these tables a first draft of recommendations was prepared by a small working group (Genevieve Veereman, Kirsten Holdt, Marijke Eyssen and Nadia Benahmed). These tables and the proposal for recommendations were circulated to the GDG two weeks prior to the face-to-face meetings (held on 13 January, 24 31 March 2014 and 28 April 2014). Recommendations were changed if important new evidence supported this change or mostly by consensus amongst the attending GDG members.

The recommendations prepared during the GDG meetings, were subsequently submitted to all GDG members for on line voting according to the Delphi method (http://www.rand.org).

In both guidelines evidence was scarce and evidence levels could mostly not be attributed. Since the ADAPTE method was applied and the great majority of recommendations were expert based, it was not possible to use GRADE for allocating levels of evidence or strengths of recommendation.

The final GDG recommendations are organized by domain and represent at least 85% consensus. In addition, the GDG identified specific areas for which clinical research is meaningful and needed as well as priorities relating to the Belgian context.

For this guideline, no formal cost-effectiveness study was conducted.

The recommendations prepared by the guideline development group were submitted to key representatives of professional and parents' associations (see colophon) who acted as stakeholders for voting according to the Delphi methods. Recommendations that did not reach 85% consensus were discussed during a face to face meeting on May 26, 2014. Stakeholders were also asked about barriers and facilitators for implementation of this guideline. Finally, the current guideline was reviewed for content prior to its publication by two independent assessors (see colophon). Subsequently the guideline was validated by CEBAM, making use of the AGREE II checklist. Declarations of interest were officially recorded.

4. CLINICAL RECOMMENDATIONS

The GDG discussed recommendations for the six domains and proposed a total of 148 recommendations. For clarity we grouped the ten positive and five negative recommendations regarding all types of interventions for all domains involved in the care of young children and adolescents with autism (Table 1).

The exhaustive list of all recommendations can be found in the scientific report. These recommendations were agreed on by over 85% of GDG members. Based on current evidence, experience and expectations the GDG also proposed research recommendations to ameliorate the prospects in the management of autism of young children, adolescents and their families (Table 2).

Finally recommendations that are specific for the Belgian context are proposed as policy recommendations (Table 3).

Table 1 – Global summary of positive and negative recommendations regarding interventions

POSITIVE AND NEGATIVE RECOMMENDATIONS		
	Reference nr recommendation in scientific report	
Psychosocial interventions		
A	37	In children and young people with autism, consider a specific social-communication intervention for the core feature of impaired reciprocal social communication and interaction. This intervention should include play based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person. Strategies should be adjusted to the child or young person's developmental level aim to increase the parents', carers', teachers' or peers' understanding of, and sensitivity and responsiveness to, the child or young person's patterns of communication and interaction include techniques to expand the child or young person's communication, interactive play and social routines. The intervention should be delivered by a trained professional. For pre-school children consider parent, carer or teacher mediation. For school-aged children consider peer mediation.
B	60	In the absence of coexisting mental health or behavioural problems (e.g. anxiety or ADHD) and if no physical disorder or environmental problem has been identified as triggering or maintaining the behaviour that challenges, offer the child or young person a psychosocial intervention as a first-line treatment.
C	92	Based on expert consensus, the GDG provided a recommendation to use augmentative communication techniques such as PECS for children with autism and impairment in adaptive behaviour.
D	96,98,99,100,101	Based on expert consensus, speech and language problems in children with autism should be addressed within a personalized project including functional objectives in the field of verbal or non-verbal communication. This program could include PECS, should be initiated early on, include speech and language therapy and involve the parents. The indication for speech therapy should be determined independent of the child's IQ and should be integrated in a multidisciplinary approach.
E	109,123	Based on expert consensus, the implementation of an educational intervention such as LEAP, an alternative program for pre-schoolers and parents, should be considered and studied to improve academic skills, learning and motor difficulties in children with autism.
F	126	Based on expert consensus, psychomotor and occupational therapy should be considered in case of co morbid developmental coordination disorder, or other well specified motor problems that interfere with daily life, but only after clinical assessment and with regular re-assessments.
G	130	It is recommended to consider a cognitive-behavioural treatment intervention (CBT) to treat anxiety in children with autism who have the required verbal and cognitive ability to engage in CBT.
Pharmacological interventions		
H	75	It is recommended to consider antipsychotic medication for managing behaviour that challenges in children and young people with autism when psychosocial or other interventions are insufficient or could not be delivered because of the severity of the behaviour.

I	88	Based on the available literature, the pharmacological agents that have shown comparable efficacy as treatment for challenging behaviour in children and young persons with autism are haloperidol, risperidone and aripiprazole.
J	136	Based on expert consensus, in the case of persistent sleep problems, it is recommended to consult with a specialist with expertise in the management of autism or paediatric sleep medicine for persistent sleep problems to consider pharmacological treatment (e.g. melatonin).
Biomedical interventions		
K	44,47,49, 89, 94, 95,103, 104, 114,120, 128,129,134,138	Biomedical interventions involving hormone therapy (secretin), immunoglobulins, chelation, HBOT and gluten- or casein-free diets are not recommended to target *overall autistic behaviour.*
L	45	Biomedical interventions involving drugs such as antibiotics, antifungals, dextrometorphan, famotidine, amantadine, benzodiazepines and antihistamines are not recommended to treat ASD.
M	46,48,50,89, 94,103,113,105	There is insufficient evidence on the effect of complementary interventions (such as acupressure, acupuncture, electro-acupuncture, and hands on facilitated communication and Qigong massage), nutritional interventions (with multivitamins and minerals, L- carnosine or L-carnitine, omega-3 fatty acids) and sensory interventions (neurofeedback and auditory integration training) or motor intervention (Kata exercise training). Therefore no recommendation can be provided for these interventions.
N	71,73	The use of isolation chambers and physical restraints should be restricted to exceptional cases where all other approaches have failed and the person and the environment need protection.
O	74	It is recommended not to use packing (wrapping in cold, wet towels).

Table 2 – Research recommendations

GDG: Research recommendations	
149	The GDG recommends to promote community based research and to explore which research designs are best applicable to the population.
150	Given a limited but encouraging amount of evidence, the GDG recommends to focus research interventions on the following domains:
	1. Augmentative communication such as Picture Exchange Communication System (PECS)
	2. Learning Experience and Alternative Program for Preschools and their Parents (LEAP)
	3. Early Start Denver model (ESDM)
	4. TEACCH model
	5. Speech and language therapy
	6. Psychopharmacological therapies for core features, challenging behaviour, associated features and coexisting conditions.

Table 3 – Policy recommendations made by the GDG

GDG Recommendations specific to the Belgian context	
151	The GDG recommends to support home based care within a network for all age groups. Home based care also addresses concerns of parents, siblings and their environment.
152	An individual plan should be elaborated for each child or adolescent with autism. This plan or road map should be discussed amongst the care providers, the child's legal representatives and the recipient. Regular assessments should redefine the recipient's participation. Therapies should be updated based on the state of the art in clinical experience and research.
153	Care networks for children and young people with autism should be equally accessible to all.
154	Care networks should integrate adapted residential care as one of the possible treatment options for children and adolescents with autism who present challenging behaviour or are in a crisis situation.
155	Education should be tailored to the needs of the children and young people with autism whether they are included in the mainstream or in the special educational system. It should be accessible to all, independent of their intellectual capacities. This includes also children with higher intellectual capacities than average.
156	Professionals should be provided with adequate training and support.

5. DISCUSSION

5.1. Best available evidence

The problems faced by children and adolescents with autism, their caretakers and families are complex. Since evidence on the various outcomes is lacking, the present guideline is mostly a consensus based guideline. However, we obtained consensus from a broad representation of and parents and professionals caring for children and adolescents with autism. The consensus was in line and never in contradiction with the, albeit limited, available evidence. In addition promising areas for further research have been identified and recommendations were made for the situation is Belgium.

5.2. How to use this guideline

GDG members strongly felt that practical and pragmatic solutions tailored to the individual situation should be offered to children and adolescents with autism and their families. It was stressed that in everyday life the biggest challenges are aggressive behaviour, associated medical conditions and sexuality. The recommendations made by the GDG are comprehensive and address these particular areas. We believe that the GDG recommendations offer a solid base for orienting care, improving existing structures or creating new ones within the available logistic context.

■ REFERENCES

1. NICE. Autism - management of autism in children and young people: NICE guideline. London: National Institute for Health and Care Excellence, 2013. CG170 Available from: http://guidance.nice.org.uk/CG170/NICEGuidance/pdf/English
2. Santé HAS. Autisme et autres troubles envahissants du developpement: interventions éducatives et thérapeutiques coordonnées chez l'enfant et l'adolescent. France: HAS; 2012. Mars 2012 Available from: http://www.anesm.sante.gouv.fr/spip.php?article398
3. Fervers B, Burgers Js Fau - Haugh MC, Haugh Mc Fau - Latreille J, Latreille J Fau - Mlika-Cabanne N, Mlika-Cabanne N Fau - Paquet L, Paquet L Fau - Coulombe M, et al. Adaptation of clinical guidelines: literature review and proposition for a framework and procedure. 2006;18(3):167-76.