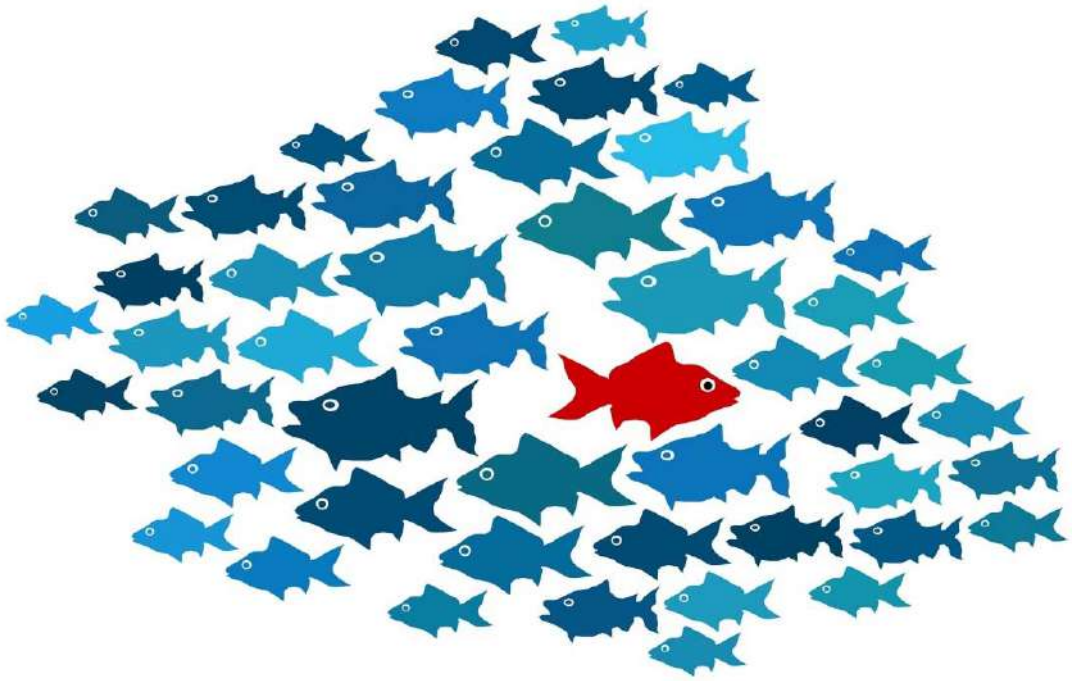
KCE REPORT 233S

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

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

## APPENDIX



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

## APPENDIX

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

# COLOPHON


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|---|---|
| Title : | Management of autism in children and young people: a good clinical practice guideline – Appendix |
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| External Validators : | Philippe Evrard (Université Paris Diderot Paris 7, France; Service de neurologie pédiatrique et des malaldies métaboliques, Hôpital universitaire Robert Debré, Assistance Publique - Hôpitaux de Paris, France), Jonathan Green (University of Manchester, United Kingdom ; Honorary Consultant Child é Adolescent Psychiatrist, Central Manchester and Manchester Childern's Hospitals University NHS Trust and Manchester Biomedical Research Centre, United Kingdom), |

| | |
|---|---|
| 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)<br>Holder of intellectual property (patent, product developer, copyrights, trademarks, etc.): Peter Vermeulen (Author of books about autism)<br>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)<br>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)<br>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),<br>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<br>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) |

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| | 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)<br>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.**<br>• **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.**<br>• **Finally, this report has been approved by common assent by the Executive Board.**<br>• **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 | 6 November 2014 (2nd print; 1st print: 04 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/2014/10.273/88 |

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 – Appendix. Good Clinical Practice (GCP) Brussels: Belgian Health Care Knowledge Centre (KCE). 2013. KCE Reports 233. D/2014/10.273/88.

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# 1. PARTICIPANTS IN THE DEVELOPMENT OF THE GUIDELINE

## 1.1. Composition of the Guideline Development Group (GDG)

**Table 1 – GDG: president and members**

| First name | Last name | Field of expertise | Affiliations |
|---|---|---|---|
| **President** | | | |
| Jan | Croonenberghs | Child psychiatrist | Ziekenhuisnetwerk Antwerpen Universitaire Kinder-en Jeugdpsychiatrie (ZNA UKJA); Referentiecentrum voor autisme (RCA) Antwerpen; Universiteit Antwerpen, Faculteit Geneeskunde, CAPRI JEUGD |
| **Members** | | | |
| Marie-Hélène | Bouchez | Psychologist | Centre de Référence pour les Troubles du spectre Autistique (CRA), Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |
| Ann | De Roeck | Linguist | De Vijver - afdeling De Hoeve, ondersteuningscentrum voor personen met autisme erkend door Vlaams Agentschap voor Personen met een Handicap (VAPH) |
| Nicolas | Deconinck | Neuropediatrician | Centre de référence pour la prise en charge des troubles autistiques (CRA) et Clinique de neurologie de l'HUDERF (Hôpital Universitaire Des Enfants Reine Fabiola); Université Libre de Bruxelles (ULB), Faculté de Médecine |
| Gaby | De Ligne | Occupational therapist | Referentiecentrum voor autisme (RCA) Universitair Ziekenhuis Brussel (Campus ZH Inkendaal) |
| Griet | Dewitte | Psychomotor therapist | Centrum voor Ontwikkelingsstoornissen (COS) Gent |
| Tine | Gheysen | Master in educational sciences | Vrije-CLB-Koepel vzw (CLB Centra voor Leerlingenbegeleiding), Afdeling Leerlingen met specifieke noden en contact Vlaams Agentschap voor Personen met een Handicap (VAPH) |
| Maryse | Hendrix | Psychologist | Agence Wallonne pour l'Integration des Personnes Handicapées (AWIPH) |
| Claire | Kagan | Psychologist | Centre Psycho-Médico-Social (PMS) de la Fédération Wallonie Bruxelles |
| Ghislain | Magerotte | Master in educational sciences | Université de Mons, Faculté de Psychologie et des Sciences de l'Education (Emeritus); Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |

| | | | |
|---|---|---|---|
| Marleen | Moonen | Neuropediatrician-Rehabilitation specialist | Referentiecentrum voor autisme (RCA) Universitair Ziekenhuis Brussel (Campus ZH Inkendaal) |
| Herbert | Roeyers | Psychologist | Referentiecentrum voor autisme (RCA) Gent; Ugent, Faculteit Psychologie en Pedagogische Wetenschappen, Vakgroep Experimenteel-Klinische en Gezondheidspsychologie |
| Sarah | Schelstraete | Parent | Parent organisation Vlaamse Vereniging Autisme vzw (VVA) |
| Marie-Vinciane | Soncarrieu | Child psychiatrist | Centre de référence pour la prise en charge des troubles autistiques (CRA) de l'HUDERF (Hôpital Universitaire Des Enfants Reine Fabiola) |
| Jean | Steyaert | Child psychiatrist | Expertisecentrum voor Autismespectrumstoornissen (ECA) en Dienst Kinderpsychiatrie UZ Leuven; KU Leuven, Faculteit Geneeskunde, Leuven Autism Research consortium |
| Flavio | Tolfo | Parent; civil engineer, master in philosophy and in applied sciences | Parent organisation Inforautisme asbl; Parent organisation Groupe d'Action qui dénonce le Manque de Places pour personnes handicapées de grande dépendance (GAMP) |
| Géraldine | Vrancken | Psychologist | Centre de Référence Autisme de Liège (CRAL) |
| Eric | Willaye | Psychologist | Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |
| Anne | Wintgens | Child psychiatrist | Centre de référence des troubles du spectre autistique (CRA) et Service de psychiatrie infanto-juvénile des Cliniques universitaires Saint-Luc; Université catholique de Louvain (UCL), Faculté de Médecine |
| Sara | Wouters | Child psychiatrist | Referentiecentrum voor autisme (RCA) Universitair Ziekenhuis Brussel (Campus AZ VUB); Psychiatrische Afdeling infants kinderen en adolescenten (PAika) Universitair Ziekenhuis Brussel |

## 1.2. Composition of the stakeholder panel

**Table 2 – Stakeholders**

| First name | Last name | Field of expertise | Affiliations |
|---|---|---|---|
| Alec | Aeby | Neuropediatrician | Belgian Society of Pediatric Neurology (BVKN-SBNP-BSPN); Hôpital Erasme (ULB), service de neuropédiatrie; Université Libre de Bruxelles (ULB), Faculté de Médecine |
| Cinzia | Agoni | Parent | Parent organisation Inforautisme asbl; Parent organisation Groupe d'Action qui dénonce le Manque de Places pour personnes handicapées de grande dépendance (GAMP) |
| Krista | Ceustermans | Speech therapist | Vlaamse Vereniging voor Logopedisten (VVL) |
| Sofie | Crommen | Child psychiatrist | Vlaamse Vereniging voor Kinder- en Jeugdpsychiatrie (VVK) |
| Bruno | Darras | Psychologist | Belgische Federatie van Psychologen- Fédération Belge des Psychologues (BFP-FBP); Centre Henri Wallon, Vaux-sous-Chèvremont |
| Jennifer | De Smet | Psychomotor therapist | Vlaamse Vereniging van Psychomotorisch Therapeuten (VVPT); Universitair Psychiatrisch Centrum KU Leuven, campus Kortenberg |
| Olivier | Fourez | Administrator | National Institute for Health and Disability Insurance (Institut national d'assurance maladie-invalidité - Rijksinstituut voor ziekte- en invaliditeitsverzekering INAMI/RIZIV) |
| Sylvie | Gérard | Administrator | Superior Health Council (Conseil Supérieur de la Santé - Hoge Gezondheidsraad CSS-HGR) |
| Freddy | Hanot | Parent | Parent organisation Association de Parents pour l'Epanouissement des Personnes avec Autisme (APEPA asbl) |
| Fabienne | Hody | Psychologist | Association des Centres et Services bruxellois pour les personnes Handicapées (ACSEH), Association des Centres de Jour de Bruxelles (ACJB); Centre de jour pour enfants Grandir, Bruxelles |
| Mireille | Johnen | Psychologist | Personne Handicapée Autonomie Recherchée (PHARE), Commission Communautaire Française (COCOF) |
| Abdelkhalak | Kajjal | Parent | Parent organisation Les briques du GAMP (Groupe d'Action qui dénonce le Manque de Places pour personnes handicapées de grande dépendance) |

| | | | |
|---|---|---|---|
| Philippe | Kinoo | Child psychiatrist | Société Belge Francophone de Psychiatrie et des Disciplines Associées de l'Enfance et de l'Adolescence (SBFPDAEA); Service de psychiatrie infanto-juvénile des Cliniques universitaires Saint-Luc |
| Jo | Lebeer | General Practitioner | Domus Medica; Universiteit Antwerpen, Faculteit Geneeskunde |
| Reinhilde | Lenaerts | Occupational therapist | Vlaams Ergotherapeutenverbond (VE vzw) |
| Koen | Lowet | Psychologist | Belgische Federatie van Psychologen- Fédération Belge des Psychologues (BFP-FBP) ; Multifunctioneel centrum Bethanië, Campus Genk |
| Christelle | Maillart | Speech therapist | Union Professionnelle des Logopèdes Francophones (UPLF); Université de Liège (Ulg), Unité de logopédie clinique, Département de Psychologie |
| Alain | Malchair | Child psychiatrist | Société Belge Francophone de Psychiatrie et des Disciplines Associées de l'Enfance et de l'Adolescence (SBFPDAEA); Centre Hospitalier Universitaire (CHU) de Liège, Service de psychiatrie et psychologie médicale; Université de Liège (Ulg), Faculté de Médecine |
| Hilde | Meganck | Teacher, master Special Educational Needs (Autisme) | GO! Onderwijs, Pedagogische begeleidingsdienst |
| Ilse | Noens | Master in educational sciences | KU Leuven, Faculteit Psychologie en Pedagogische Wetenschappen |
| Etienne | Oleffe | Parent | Parent organisation Association Francophone d'Aide aux Handicapés Mentaux (AFrAHM) |
| Hilde | Olivié | Neuropediatrician-Rehabilitation specialist | Stijn vzw, zorgorganisatie erkend door Vlaams Agentschap voor Personen met een Handicap (VAPH); Centrum voor Ontwikkelingsstoornissen (COS) en Expertisecentrum voor Autismespectrumstoornissen (ECA), UZ Leuven |
| Els | Ortibus | Neuropediatrician-Rehabilitation specialist | Belgian Society of Pediatric Neurology (BVKN-SBNP-BSPN); Dienst Kindergeneeskunde en Centrum voor Ontwikkelingsstoornissen (COS), UZ Leuven; KU Leuven, Faculteit Geneeskunde |
| Cis | Schiltmans | Parent | Parent organisation Vlaamse Vereniging Autisme vzw (VVA) |
| Eric | Schoentjes | Child psychiatrist | Vlaamse Vereniging voor Kinder- en Jeugdpsychiatrie (VVK); Dienst Kinderpsychiatrie UZ Gent; Ugent, Faculteit Geneeskunde |

| | | | |
|---|---|---|---|
| Anne | Taymans | Psychomotor therapist | Union Professionnelle Belge des Psychomotriciens Francophones (UPBPF); Centre d'activités La Baraque, Louvain la Neuve |
| Francis | Turine | Psychologist | Fédération des Structures Psycho-Socio-Thérapeutiques (FSPST) (Conventions Inami 7.74) |
| Julie | Vandemeulebroecke | Psychomotor therapist | Vlaamse Vereniging van Psychomotorisch Therapeuten (VVPMT) |
| Philippe | Van Vlaenderen | General Practitioner | Société scientifique de Médecine Générale (SSMG) |
| Peter | Vermeulen | Psychologist | Kennis- en ondersteuningscentrum Autisme Centraal |
| Marek | Wojciechowski | Pediatrician | Belgische Vereniging voor Kindergeneeskunde/ Société Belge de Pédiatrie (BVK-SBP); Dienst Pediatrie Universitair Ziekenhuis Antwerpen (UZA) |

## 1.3. External experts

**Table 3 – External experts**

Note: external experts were invited to be part of the GDG or stakeholder group, they provided feedback but did not attend the face to face meetings

| First name | Last name | Field of expertise | Affiliations |
|---|---|---|---|
| Pascale | Grevesse | Speech therapist | Centre de Référence pour les Troubles du spectre Autistique (CRA), Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |
| Vincent | Ramaekers | Neuropediatrician | Centre de Référence Autisme de Liège (CRAL); Centre Hospitalier Universitaire (CHU) de Liège; Université de Liège (Ulg), Faculté de Médecine |
| An | Thijs | Teacher | Vlaams Verbond van het Katholiek Buitengewoon Onderwijs (VVKBuO); Vlaams Secretariaat van het Katholiek Onderwijs (VSKO) |

## 1.4. Participants to the scoping meeting

**Table 4 – Persons participating in the scoping meeting**

| First name | Last name | Field of expertise | Affiliations |
|---|---|---|---|
| **Members of the Guideline Development Group (GDG)** | | | |
| Jan | Croonenberghs | Child psychiatrist | Ziekenhuisnetwerk Antwerpen Universitaire Kinder-en Jeugdpsychiatrie (ZNA UKJA); Referentiecentrum voor autisme (RCA) Antwerpen; Universiteit Antwerpen, Faculteit Geneeskunde, CAPRI JEUGD |
| Tine | Gheysen | Master in educational sciences | Vrije-CLB-Koepel vzw (CLB Centra voor Leerlingenbegeleiding), Afdeling Leerlingen met specifieke noden en contact Vlaams Agentschap voor Personen met een Handicap (VAPH) |
| Maryse | Hendrix | Psychologist | Agence Wallonne pour l'Integration des Personnes Handicapées (AWIPH) |
| Ghislain | Magerotte | Master in educational sciences | Université de Mons, Faculté de Psychologie et des Sciences de l'Education (Emeritus); Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |
| Herbert | Roeyers | Psychologist | Referentiecentrum voor autisme (RCA) Gent; Ugent, Faculteit Psychologie en Pedagogische Wetenschappen, Vakgroep Experimenteel-Klinische en Gezondheidspsychologie |
| Jean | Steyaert | Child psychiatrist | Expertisecentrum voor Autismespectrumstoornissen (ECA) en Dienst Kinderpsychiatrie UZ Leuven; KU Leuven, Faculteit Geneeskunde, Leuven Autism Research consortium |
| Flavio | Tolfo | Parent; civil engineer, master in philosophy and in applied sciences | Parent organisation Inforautisme asbl; Parent organisation Groupe d'Action qui dénonce le Manque de Places pour personnes handicapées de grande dépendance (GAMP) |
| Eric | Willaye | Psychologist | Service Universitaire Spécialisé pour personnes avec Autisme (Fondation SUSA asbl) à l'Université de Mons |
| **Members of the stakeholder panel** | | | |
| Cinzia | Agoni | Parent | Parent organisation Inforautisme asbl; Parent organisation Groupe d'Action qui dénonce le Manque de Places pour personnes handicapées de grande dépendance (GAMP) |
| Geert | Devos | Teacher | Onderwijssecretariaat van de Steden en Gemeenten van de Vlaamse Gemeenschap (OVSG), project Autisme Heynsdaele |

| | | | |
|---|---|---|---|
| Olivier | Fourez | Administrator | National Institute for Health and Disability Insurance (Institut national d'assurance maladie-invalidité - Rijksinstituut voor ziekte- en invaliditeitsverzekering INAMI/RIZIV) |
| Sylvie | Gérard | Administrator | Superior Health Council (Conseil Supérieur de la Santé - Hoge Gezondheidsraad CSS-HGR) |
| Freddy | Hanot | Parent | Parent organisation Association de Parents pour l'Epanouissement des Personnes avec Autisme (APEPA) |
| Cis | Schiltmans | Parent | Parent organisation Vlaamse Vereniging Autisme vzw (VVA) |
| Katelijne | Van Hoeck | Medical doctor, master in preventive youth health care | Permanente Ondersteuningscel Centra voor Leerlingbegeleiding Gemeenschapsonderwijs (CLB GO!) |

## 1.5. Composition of the KCE expert team

**Table 5 – KCE team**

| KCE member | Field of expertise, Specific role |
|---|---|
| Geneviève Veereman | Principal Investigator<br>Pediatric Gastroenterologist, MD, PhD |
| Marijke Eyssen | Project Coordinator and scientific research<br>Neuropediatrician, Rehabilitation specialist, MD<br>Also affiliated to: Centre for ambulatory rehabilitation, Lovenjoel |
| Kirsten Holdt Henningsen | Scientific research and methodological support<br>Physiotherapist, Masters in Health Administration (MHA) |
| Nadia Benahmed | Scientific research<br>Master in Public Health; Master of Advanced Study in Epidemiology and Statistical Methods; Interuniversity Certificate in Health Economics |
| Wendy Christiaens | Scientific research and methodological support<br>Sociologist, PhD |
| Kristel De Gauquier | Program Director |

## 1.6. Composition of the scientific validation team

**Table 6 – External Assessors**

| External Assessor | Field of expertise, Affiliation |
|---|---|
| Philippe Evrard | Professor-Emeritus Neuropediatrics, 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 | Professor of Child & Adolescent Psychiatry, University of Manchester, United Kingdom; Honorary Consultant Child & Adolescent Psychiatrist, Central Manchester and Manchester Children's Hospitals University NHS Trust and Manchester Biomedical Research Centre, United Kingdom. |

**Table 7 – CEBAM validators**

| | Field of expertise, Affiliation, Specific role |
|---|---|
| Trudy Bekkering | Methodological expert; Belgian Centre for Evidence-Based Medicine (CEBAM); CEBAM validator |
| Hans Hellemans | Child psychiatrist; Ziekenhuisnetwerk Antwerpen Universitaire Kinder-en Jeugdpsychiatrie (ZNA UKJA) Campus Hoge Beuken Hoboken, Referentiecentrum voor autisme (RCA) Antwerpen; Validator-Guideline user |
| Patrik Vankrunkelsven | General Practitioner; Academisch Centrum voor Huisartsgeneeskunde KU Leuven; Belgian Centre for Evidence-Based Medicine (CEBAM); President of CEBAM validation meeting |

# 2. SEARCH STRATEGIES

## 2.1. Search strategy for guidelines

**Table 8 – Search strategy for guidelines on autism in Medline**

| Date | June 24, 2013 |
|---|---|
| Database | Medline, Medline in progress (via OVID) |
| Search Strategy | 1 asperger$.mp. (1920)<br>2 cerebroatrophic hyperammonemia$.mp. or Rett Syndrome/ (1847)<br>3 (kanner$ adj (disorder or syndrome$)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier] (25)<br>4 (pervasive$ adj2 (development$ or neurodevelopment$)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier] (4764)<br>5 (pddnos or pdd nos).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier] (267)<br>6 (rett$ adj (disorder$ or syndrome$)).ab,ti. (2243)<br>7 (pddnos or pdd nos).ab,ti. (267)<br>8 asperger syndrome.af,ab,ti. (1615)<br>9 autistic disorder.af,ab,ti. (16001)<br>10 child development disorders, pervasive.af,ab,ti. (4018)<br>11 rett syndrome.af,ab,ti. (2358)<br>12 exp Guideline/ (24217)<br>13 guideline.ab,ti. (21929)<br>14 guideline.pt. (15387)<br>15 practice guideline.pt. (18239)<br>16 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 (22219)<br>17 12 or 13 or 14 or 15 (43294)<br>18 16 and 17 (33) |
| Notes | Population search based on NICE guideline 2013, provided to KCE prior to publication |

**Table 9 – Search results - Guidelines on autism**

| Date: June 24, 2013 | Languages: English, Dutch, French | | | |
|---|---|---|---|---|
| Search engine | **URL** | **Search term** | **Number of hits** | **Included** |
| **OVID Medline** | http://www.ovid.com/ | Table 8 – Search strategy for guidelines on autism in Medline | 30 | 3 |
| **G-I-N guideline resource** | http://www.g-i-n.net/ | autis* OR asperger* OR autistic disorder OR asperger syndrome OR child development disorder OR rett syndrome | 8 | 6 |
| **National Guideline Clearinghouse** | http://www.guideline.gov/ | autism | 71 | 5 |
| **NICE** | http://www.nice.org.uk/ | autism | 1 | 1 |

## 2.2. Selection of guidelines based on in/ exclusion criteria

After screening based on titles and abstracts and removal of obvious duplicate guidelines, 10 guidelines found in the literature or on websites were selected. The full text of these 9 guidelines was evaluated by a researcher from the KCE team (KH) in accordance with the in- and exclusion criteria stated in Chapter 2 of the scientific report. Of the 10 retrieved guidelines, 5 guidelines were excluded because they were duplicates. Finally, 5 guidelines were retained for an evaluation of the methodological quality (Agree II tool).

Participants to the scoping meeting, held on October 8th 2013, suggested 5 additional guideline documents. The full text of these documents was assessed by a researcher from the KCE team (KH or GV). One of these guidelines was a Swedish HTA report {SBU, 2013 #60} and another was a practical implementation document based on the guideline by the Haute Autorité de la Santé (HAS). The 3 remaining documents were quality-appraised by the AGREE II tool. A list the 8 guidelines that were quality appraised is presented below:

**Table 10 – Guidelines selected for quality appraisal based on literature search and results of critical appraisal (Agree II)**

| Source | Year | Title | Recommended/Not recommended |
|---|---|---|---|
| **HAS (FRANCE)** | 2012 | Recommandations pour la pratique professionnelle du diagnostic de l'autisme. Recommandations pour la pratique Clinique. [Autism and other severe developmental disorders: treatment of children and adolescents]. | Recommended |
| **Academy of Medicine Singapore-Ministry of Health** | 2010 | Academy of Medicine Singapore-Ministry of Health clinical practice guidelines: Autism Spectrum Disorders in pre-school children. | Not recommended |
| **New Zealand Ministry of Education - National Government Agency** | 2008 | Treatment and management of ASD. In: New Zealand autism spectrum disorder guideline. | Not Recommended |
| **American Academy of Paediatrics** | 2012 | Nonmedical interventions for children with ASD: recommended guidelines and further research needs. | Not recommended |
| **NICE (UK)** | 2013 | Autism spectrum disorders in children and young people (CG170). | Recommended |

**Table 11 – Guidelines suggested by the GDG and results of critical appraisal**

| Source | Year | Title | Recommended/Not recommended |
|---|---|---|---|
| **National Autism Center (NAC), USA** | 2009 | National Standards Report | Not Recommended |
| **Health Council of the Netherlands** | 2009 | Autism spectrum disorders: a lifetime of difference | Not Recommended |
| **Hoge Gezondheidsraad (België)** | 2013 | Levenskwaliteit van jonge kinderen met autism en hun gezin | Not Recommended |
| **SBU- Swedish Council on Health Technology Assessment** | 2013 | Autismspektrumtillstånd | Excluded: Swedish HTA |
| **UNAPEI (Fédération d'associations française de représentation et de défense des intérêts des personnes handicapées mentales et de leurs familles)** | 2013 | Autisme : les recommandations de bonnes pratiques professionnelles / Savoir-être et savoir-faire. | Excluded: practical implementation tool based on the HAS Guideline |

# 3. CRITICAL APPRAISAL

## 3.1. AGREE scores for selected guidelines

**Table 12 – AGREE II instrument**

| Critical appraisal of clinical practice guidelines - AGREE II |
|---|
| **Domain 1. Scope and Purpose** |
| 1. The overall objective(s) of the guideline is (are) specifically described. |
| 2. The health question(s) covered by the guideline is (are) specifically described. |
| 3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described. |
| **Domain 2. Stakeholder Involvement** |
| 4. The guideline development group includes individuals from all the relevant professional groups. |
| 5. The views and preferences of the target population (patients, public, etc.) have been sought. |
| 6. The target users of the guideline are clearly defined. |
| **Domain 3. Rigour of Development** |
| 7. Systematic methods were used to search for evidence. |
| 8. The criteria for selecting the evidence are clearly described. |
| 9. The strengths and limitations of the body of evidence are clearly described. |
| 10. The methods for formulating the recommendations are clearly described. |
| 11. The health benefits, side effects, and risks have been considered in formulating the recommendations. |
| 12. There is an explicit link between the recommendations and the supporting evidence. |
| 13. The guideline has been externally reviewed by experts prior to its publication. |
| 14. A procedure for updating the guideline is provided. |
| **Domain 4. Clarity of Presentation** |
| 15. The recommendations are specific and unambiguous. |
| 16. The different options for management of the condition or health issue are clearly presented. |
| 17. Key recommendations are easily identifiable. |
| **Domain 5. Applicability** |
| 18. The guideline describes facilitators and barriers to its application. |

19. The guideline provides advice and/or tools on how the recommendations can be put into practice.
20. The potential resource implications of applying the recommendations have been considered.
21. The guideline presents monitoring and/ or auditing criteria.

**Domain 6. Editorial Independence**

22. The views of the funding body have not influenced the content of the guideline.
23. Competing interests of guideline development group members have been recorded and addressed.

## 3.2. Guideline quality appraisal results

**Table 13 – Agree II scores of identified guidelines**

| Source | Title | Standardized Score | | | | | | Final Appraisal |
|---|---|---|---|---|---|---|---|---|
| | | Scope | Stakeholder involvement | Rigour of development | Clarity | Applicability | Editorial Independence | |
| Singapore (AMS-MOH) | Autism Spectrum Disorders in Pre-School Children | 83% | 58% | 13% | 89% | 40% | 4% | Excluded |
| New Zealand (Ministries of Health and Education) | Autism Spectrum Disorder: Guideline | 89% | 78% | 84% | 94% | 58% | 58% | Excluded (however, part gastroenterology was included because this was the only guideline dealing with this) |

| Source | Title | Standardized Score | | | | | | Final Appraisal |
|---|---|---|---|---|---|---|---|---|
| US (American Academy of Paediatrics) | Nonmedical Interventions for Children With ASD: Recommended Guidelines and Further Research Needs | 78% | 50% | 62% | 64% | 21% | 83% | Excluded |
| France (HAS) | Autisme et autres TED : Interventions éducatives et thérapeutiques coordonnées chez l'enfant et l'adolescent | 86% | 86% | 58% | 83% | 25% | 70% | **Included** |
| UK (NICE) | The management and support of children and young people on the autism spectrum | 92% | 92% | 88% | 94% | 38% | 79% | **Included** (Guideline was just published, some items under applicability are dealt with post-publication) |
| US (NAC) | National Standards Report | 86% | 28% | 45% | 47% | 29% | 0% | Excluded |
| HGRCSS | | 89% | 69% | 17% | 61% | 27% | 73% | Excluded |
| Dutch Health Council | | 81% | 56% | 28% | 61% | 17% | 46% | Excluded |

# 4. DSM-5 AND ICD-10 DEFINITIONS OF AUTISM

## 4.1. DSM-5: Autism Spectrum Disorder 299.00 (F84.0)

*Source : Diagnostic and Statistical Manual of Mental Disorders: DSM-5 – fifth edition- ISBN 978-0-89042-554-1*

**Table 14 – Diagnostic criteria autism according to DSM-5**

| | | | |
|---|---|---|---|
| **A** | Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive) | 1. | Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions. |
| | | 2. | Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication. |
| | | 3. | Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative paly or in making friends; to absence of interest in peers. |
| | *Specify current severity:*<br>*Severity is based on social communication impairments and restricted repetitive patterns of behavior (see Table below).* | | |
| **B** | Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive) | 1. | Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases). |
| | | 2. | Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day). |
| | | 3. | Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest). |

| | | |
|---|---|---|
| | | 4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). |
| | *Specify current severity:*<br>*Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table below).* | |
| **C** | Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life). | |
| **D** | Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning. | |
| **E** | These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co-morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level. | |

*Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.*

*Specify if:*
*With or without accompanying intellectual impairment*
*With or without accompanying language impairment*
*Associated with a known medical or genetic condition or environmental factor*
*(Coding note: Use additional code to identify the associated medical or genetic condition.)*
*Associated with another neurodevelopmental, mental, or behavioral disorder*
*(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)*
*With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119-120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)*

**Table 15 - Severity levels for autism spectrum disorder**

| Severity level | Social communication | Restricted, repetitive behaviors |
|---|---|---|
| **Level 3**<br>**"Requiring very substantial support"** | Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches | Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. |
| **Level 2**<br>**"Requiring substantial support"** | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and how has markedly odd nonverbal communication. | Inflexibility of behavior, difficulty coping with change, or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action. |
| **Level 1**<br>**"Requiring support"** | Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions, and clear examples of atypical or unsuccessful response to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to- and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful. | Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of organization and planning hamper independence. |

## 4.2. ICD-10 Criteria for "Childhood Autism"

Source: *World Health Organization. (1992).* International classification of diseases: Diagnostic criteria for research *(10th edition). Geneva, Switzerland: Author in* [http://www.iancommunity.org/cs/autism/icd10_criteria_for_autism](http://www.iancommunity.org/cs/autism/icd10_criteria_for_autism)

**Table 16 – Diagnostic criteria autism according to ICD-10**

| | | | | |
|---|---|---|---|---|
| **A** | **Abnormal or impaired development is evident before the age of 3 years in at least one of the following areas** | 1. | receptive or expressive language as used in social communication | |
| | | 2. | the development of selective social attachments or of reciprocal social interaction | |
| | | 3. | functional or symbolic play | |
| **B** | **A total of at least six symptoms from (1), (2) and (3) must be present, with at least two from (1) and at least one from each of (2) and (3)** | 1. | Qualitative impairment in social interaction are manifest in at least two of the following areas | *failure adequately to use eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction* |
| | | | | *failure to develop (in a manner appropriate to mental age, and despite ample opportunities) peer relationships that involve a mutual sharing of interests, activities and emotions* |
| | | | | *lack of socio-emotional reciprocity as shown by an impaired or deviant response to other people's emotions; or lack of modulation of behavior according to social context; or a weak integration of social, emotional, and communicative behaviors* |
| | | | | *lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. a lack of showing, bringing, or pointing out to other people objects of interest to the individual)* |
| | | 2. | Qualitative abnormalities in communication as manifest in at least one of the following areas | *delay in or total lack of, development of spoken language that is not accompanied by an attempt to compensate through the use of gestures or mime as an alternative mode of communication (often preceded by a lack of communicative babbling);* |

| | | |
|---|---|---|
| | | *relative failure to initiate or sustain conversational interchange (at whatever level of language skill is present), in which there is reciprocal responsiveness to the communications of the other person* |
| | | *stereotyped and repetitive use of language or idiosyncratic use of words or phrases* |
| | | *lack of varied spontaneous make-believe play or (when young) social imitative play* |
| | 3. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities are manifested in at least one of the following | *An encompassing preoccupation with one or more stereotyped and restricted patterns of interest that are abnormal in content or focus; or one or more interests that are abnormal in their intensity and circumscribed nature though not in their content or focus* |
| | | *Apparently compulsive adherence to specific, nonfunctional routines or rituals* |
| | | *Stereotyped and repetitive motor mannerisms that involve either hand or finger flapping or twisting or complex whole body movements* |
| | | *Preoccupations with part-objects of non-functional elements of play materials (such as their oder, the feel of their surface, or the noise or vibration they generate)* |
| **C** | **The clinical picture is not attributable to the other varieties of pervasive developmental disorders; specific development disorder of receptive language (F80.2) with secondary socio-emotional problems, reactive attachment disorder (F94.1) or disinhibited attachment disorder (F94.2); mental retardation (F70-F72) with some associated emotional or behavioral disorders; schizophrenia (F20.-) of unusually early onset; and Rett's Syndrome (F84.12).** | |

# 5. GDG DISCUSSION OF EVIDENCE RETRIEVED BY NICE AND HAS BY DOMAIN

## 5.1. Organisation and delivery of care (GDG 1 on 13-1-2014)

**Table 17 – Evidence and GDG discussion on domain 1: organisation and delivery of care**

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | KCE | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|
| **NICE GUIDELINE** | **HAS GUIDELINE** | | | | | |
| | | **Summary** | | **COMMENTS 1 - 3** | **COMMENTS 4-6** | **COMMENTS 7-9** |
| **All staff working with children and young people with autism should have an understanding of autism.** | | y=11<br>n=0<br>na/?=0 | x | 1) Most preferrable: all people in the organisation.<br>2) Specify what is meant by "understanding", references should be DSM-V or ICD-10<br>3) Emphasise on the need for training. A comprehensive training(including medical/psychological) for all staff having an overseeing, coordinative function; A basic training for everyone working with this population. | 4) "should" OK mais la question principale est "HOW" et où trouver les budgets!<br>5) "should" OK mais la question principale est "HOW" et où trouver les budgets! | |
| **In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment;** | | y=11<br>n=0<br>na/?=0 | x | 1) What are the criteria for reasonable and appropriate adjustments? | | |
| **Children and young people with autism should have access** | **Cfr below** | y=11<br>n=0<br>na/?=0 | x | 1) The main tool for this management is the American "IEP" and the French "PPI" 'Projet Personnalisé | | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | | <70% yes | important comments | | |
|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | |
| | | | Summary | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| **to a keyworker approach in order to manage and coordinate treatment, care and support, including the management of transitions, for the child or young person with autism and their family and carers.** | | | | | d'Intervention"<br>2) OK on the level of a school or institution(eg. A child psychiatric service or a MPI. Unrealistic(??) on the level of a geographic area (city; province; Flanders) | | |
| **Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities.** | | | y=11<br>n=0<br>na/?=0 | x | 1) And also access to schools – schooling is compulsory from 6 to 18 years of age. And the "pupil/student status " is the most "valorized" status in Belgium for these children and adolescents ! And for 7 hours a day, and more than 30 h/week !!!! | | |
| **Children and young people with autism, and their family and carers, should have easy access to short breaks.** | | | y=11<br>n=0<br>na/?=0 | x | 1) Need for emergency care in crisis situations<br>2) These short breaks are essential for the quality of life of the whole family;<br>3) But not systematically for all persons in all conditions.Emphasise on the need for crisis intervention. | 4) Though it is illusive and perhaps contraproductive to generalize this statement. It is essential in (very) severe cases, seldom in mild cases.<br>5) Zeker een noodzaak vanuit mijn ervaring met gezinnen met kinderen met ASS ! | |
| **Children and young people with autism, and their family and carers, should be provided with post-diagnosis information about services available** | | | y=11<br>n=0<br>na/?=0 | x | 1) No post-diagnosis specialised services available in Brussels or Wallonia for the recommended good practices<br>2) Very important, with a special attention to the (evidence-based) practices used in these services, proposed in the Project of the | 4) For the Belgian situation, I would somewhere add the specific services provided by Reference centres.<br>5) Problème de la "saturation" des centres de reference pour les TSA; (INAMI) ainsi que des Services d'Aide Précoce (AWIPH)<br>6) Aandacht voor verschillende | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | KCE | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|
| **NICE GUIDELINE** | **HAS GUIDELINE** | | | | | |
| | | **Summary** | | **COMMENTS 1 - 3** | **COMMENTS 4-6** | **COMMENTS 7-9** |
| **and support, for example a family support worker.** | | | | services !<br>3) Question is whether this is not best provided by the diagnostic service | manier van verwerken van diagnoses…informatie over zorg is zeker nodig, maar het tijdstip waarop men die info nodig heeft varieert nogal sterk in mijn ervaring. Sommige ouders/lln krijgen die liefst meteen samen met diagnose ; voor andere gaat de info over zorg verloren op moment van krijgen diagnose…een zekere 'aanklampendheid' kan misschien zinvol zijn of een termijn waarop nog eens gepolst wordt of er vraag is naar ondersteuning (evt via reguliere netwerk bv. CLB) | |
| **Treatment and care of children and young people with autism should involve shared decision making and a collaborative approach that takes into account service user preferences.** | **Cfr below** | y=11<br>n=0<br>na/?=0 | x | 1) Should be work in partnership: a close collaboration between professionals and parents is crucial in the whole process. Not only taking into account people's preferences, but really work together.<br>2) See IEP and PPI ! with the effective collaboration of the child/adolescent and the parents !<br>3) If possible | | |
| **All children and young people with autism should have access to healthcare and social care services, including mental health services, and access should not be restricted based on a child's intellectual ability, autism diagnosis, or any other eligibility criteria.** | | y=10<br>n=1<br>na/?=0 | x | 1) Children with autism are denied reimbursement of logo-therapy services based on insufficient I.Q. Speech therapy is beneficial even with non verbal persons<br>2) OK for first line health care. In second and third line health care inclusion/exclusion based on the intellectual ability is necessary.<br>3) It is not realistic not to differentiate. Mental health services cannot cope with the amount of potential demands, in particular for specific categories (e.g. severe challenging behaviour) and the provider should be able to | 4) Toegang toe moet voorzien zijn zonder restricties…maar in mijn ervaring gebeurt soms ook het omgekeerde…men 'eist' ondersteuning op omwille van een diagnose waar dat niet altijd nodig is…ik kan alleen niet opmaken of deze richtlijnen daar iets kunnen aan doen | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | | |
| | | | Summary | | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| | | | | | | develop eligibility criteria in order to give optimal care to an optimal number of cases. Risk of “service clogging” | | |
| | | | | | | | | |
| | **Need of a coherent multidisciplinary approach.** | | y=11<br>n=0<br>na/?=0 | | x | 1) See parents as one of the disciplines. | | |
| | **Define rules for multi (trans) disciplinary approach in the same or in different institutions.** | | y=10<br>n=0<br>na/?=1 | | x | 1) Based on autistic people's problems with generalization.<br>2) ? y though too strict rules (one-size-for-all risk) may choke the possibility to individualize treatments | | |
| | **Rules should define work plan including timing and identify coordinator.** | | y=9<br>n=0<br>na/?=2 | | x | 1) ? Y rules should define the existence of work plan and broadly the areas to be covered and the need for EBT; not too precise details : see previous comment<br>2) Work plan should be an individualised plan, measured to the specific needs of the individual person/child with autism | | |
| | **Rules should be formalised within an institution, in conventions with other professionals, in networks.** | | y=11<br>n=0<br>na/?=0 | | x | 1) And parents<br>2) At least general rules concerning organisation, need for EBT; | | |
| | **The rules should be known by all professionals.** | | y=9<br>n=0<br>na/?=2 | | | 1) Gekend of weten waar ze terug te vinden zijn? | | |
| | **The rules/action plan should be part of the personalised reimbursement and educational plan.** | ??? | y=7<br>n=1<br>na/?=3 | x | x | 1) Would be nice if possible<br>2) From which page in HAS does this come? (Answer: p 310 de l'Argumentaire Scientifique)<br>3) How is the plan monitored and adapted? | 4) See the PIA (Plan Individuel d’apprentissage) in the Fédération Wallonie-Bruxelles specialised schools and in inclusive schools! And the Projet Individualisé in the AWIPH and COCOF facilities !<br>It’s also important for the services paid by the INAMI/RIZIV!<br>5) Unclear what is meant<br>6) See VAPH in Flanders | 7) Privacy?<br>8) What do we excactly mean by reimbursement plan (to discuss)<br>9) Ik heb geen goeie ervaringen met té formalistische verplichtingen om ondersteuning te kunnen krijgen. Een plan en regels zijn geen garantie voor hulp aan de |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | | <70% yes | important | | | |
|---|---|---|---|---|---|---|---|---|
| **NICE GUIDELINE** | **HAS GUIDELINE** | | | | | | | |
| | | | **Summary** | | | **COMMENTS 1 - 3** | **COMMENTS 4-6** | **COMMENTS 7-9** |
| | | | | | | | | juiste personen op het juiste moment. |
| **Cfr above** | **Develop a personalised program based on evaluation with appropriate tools and on observation in daily life, and in agreement with the patient, the parents and all professionals involved.** | | y=11<br>n=0<br>na/?=0 | | x | 1) see above<br>2) Bij voorkeur op basis van een bio-psycho-sociaal model (bv. ICF) | | |
| **Cfr above** | **Assign the task of coordinator to one of the professionals in order to guarantee the coherence and continuity of care.** | | y=11<br>n=0<br>na/?=0 | | x | 1) Parents involvement and evaluation of the program<br>2) In close collaboration with the parents, mainly for young children !<br>3) OK on the level of a school or institution(eg. A childpsychiatric service ir a MPI. Unrealistic(??) on the level of a geographic area (city; province; Flanders) | 4) Parents / caretaker also have a role in coordination, in particular in long-term follow up. Otherwise risk at transitions<br>5) Coordinator could change over time and context.<br>6) Haalbaarheid? Vaak wisseling in diensten die personen met ASS begeleiden. In Vlaanderen werd dit in het verleden vaak opgenomen door thuisbegeleidingsdiensten (trajectbegeleiding), er bestaat iets als ‘contactpersoon’ binnen VAPH en ‘contactpersoon-aanmelder’ binnen IJH die gelijkaardige opdrachten hebben (voor de ruimere doelgroep uiteraard). Mogelijkheden binnen diensten ondersteuningsplan (DOP)? Bij diensten die breder werken (bv. CLB) zie ik dit momenteel minder haalbaar op lange termijn | |
| | **A medical doctor or director of an institution will be responsible for overseeing or** | AC_CEPT (DIS-CUSS) | y=6<br>n=3<br>na/?=2 | x | x | 1) Someone has to take the lead, but there is no reason to define this person's qualifications in these terms.<br>2) Why only an M.D. or a director of institution as coodinator? Other experts are available | 4) The overseeing task has to be executed by a person who had a comprehensive training(including medical/psychiatric/neurological/psychological)<br>5) Define which institutions: reference | 7) Indeed needs to be discussed. Is this not too medical driven?<br>8) Autism is a medical diagnosis, the presence of a medical doctor in the team is |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | | <70% yes | important | | | |
|---|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | | |
| | | | Summary | | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| | **delegating the coordination task.** | | | | | 3) A non-medical coordinator is fine as well | centre? Psychiatrist?<br>6) probablement diffcile pour un directeur de tout coordonner, nécessité de déléguer | very important<br>9) Eindverantwoordelijkheid ligt uiteindelijk altijd bij directie of niet? In realiteit wordt die vaak gedelegeerd…maar de personen die de opdracht krijgen, moeten dan wel geïnformeerd worden over hun verantwoordelijkheden en de consequenties als er iets misloopt? |
| | **A file (case record, dossier) is the source document for communication.** | | y=11<br>n=0<br>na/?=0 | | x | 1) Communicatie tussen wie? | | |
| | **The file should contain all relevant information on the patient: personalised project, evaluations, treatment plan, specific interventions.** | | y=11<br>n=0<br>na/?=0 | | | 1) Need to know informative…niet nice to know anders risico dat het onoverzichtelijk wordt ; wie bepaalt welke info op een bepaald moment niet meer 'geldig' is? Of 'achterhaald'? Moet ook kunnen weergegeven worden | | |
| | **Sharing the file necessitates parental consent, in line with the rules of duty of professional confidentiality.** | | y=11<br>n=0<br>na/?=0 | | x | 1) Sharing with persons outside the setting: need for consent from parents and youngster<br>2) Parents should have the right to protect specific parts of file for caregivers who do not need this (confidential) information: e.g. genetic, familial information is not needed for special educ. teachers<br>3) In vlaanderen geregeld via Decreet rechtspositie van de minderjarige in de jeugdhulp (IJH) voor de minderjarigen lijkt mij | | |
| | **In professional communication, it is recommended to use the International Classification of** | | y=6<br>n=3<br>na/?=2 | x | x | 1) It would be strange to ignore DSM-5<br>2) In most specialized centres in Flanders there is a tradition of using the DSM classification. In the NICE guidelines both classifications are | 4) DSM-V should be considered | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | |
| | | Summary | | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| | **Diseases (ICD-10) and the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).** | | | | mentioned. The new DSM-5 classification has the advantage to differ between different levels of need for intervention.<br>3) Add DSM in Belgium | | |
| | **A go-between notebook is recommended to support communication between the professionals and the parents and child.** | y=10<br>n=0<br>na/?=1 | | x | 1) But more up to data tools could be used as well<br>2) If strict rules on confidentiality, possibility to hide specific parts of notebook etc.<br>3) Bv. P-ASS-poort (wordt o.a. gebruikt bij overgangen van basis naar secundair voor lln met ASS) | | |
| | **Upon transfer between institutions (medical/social) a contact person (referent) should be kept.** | y=10<br>n=0<br>na/?=1 | | x | 1) Idealiter maar niet altijd haalbaar ; werkbelasting van de 'vroegere' betrokkenen vaak in die mate groot dat ze nog weinig beschikbaar zijn om voor ex-cliënten iets te betekenen | | |
| | **Networking, collaboration and regular meetings should be organized between professionals.** | y=9<br>n=0<br>na/?=2 | | x | 1) Parents or legal responsible must be part of the team. "Nothing about us without us"<br>2) Teveel 'formeel' vastgelegde vergaderingen zijn niet altijd productief. Ad hoc rond bepaalde thema's mensen kunnen samenbrengen is vaak efficiënter. Mogelijkheden die er momenteel zijn om expertise uit te wisselen tussen sectoren (bv. vanuit SENvzw) moeten zeker verder gestimuleerd worden | | |
| | **The Reference centres for Autism have a specific role in supporting the networking.** | y=9<br>n=0<br>na/?=2 | | x | 1) What happens after the diagnostic by the Reference Centre? In French speaking community there is a cruel lack of specialized services<br>2) This role is ESSENTIAL for each person with autism. It has to be more | 4) Is this role too much centralized. It concerns then a very high number of patients. To discuss<br>5) Weinig ervaring met ondersteuning van 'netwerken' op dit moment vanuit referentiecentra (mogelijk owv | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | |
| | | Summary | | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| | | | | | recognized and paid !<br>3) Actually RCA's have the possibility of coordination sessions | tijdsgebrek)…referentiecentra zijn in mijn ervaring vooral bij de diagnostiek betrokken en bij verder uittekenen trajecten van kinderen, jongeren en hun ouders…maar minder bij ondersteunen andere professionelen (maar ben intussen wel al een paar jaar weg uit het echte 'veldwerk') | |
| | **Institutions, especially hospitals, should offer protocols to facilitate first contacts.** | y=9<br>n=0<br>na/?=2 | x | | 1) I would remove especially hospitals<br>2) See for example the KAPPA system (Choice and Core sessions) to limit waiting lists.<br>3) Mij niet helemaal duidelijk wat hiermee bedoeld wordt. Eerste contacten met wie? Lijkt me vooral gepersonaliseerd te moeten verlopen…'k weet niet of protocollen hier veel kunnen toe bijdragen | | |
| | **A medical examination by the medical doctor chosen by the parents should be offered at least yearly.** | y=8<br>n=2<br>na/?=1 | x | | 1) Very crucial, since medical problems should always been excluded before other treatments start.<br>2) Coordinated medical examination planning in the hospital for multiple checkups<br>3) Not always; only in the case of pharmacotherapy and / or medical comorbidity. | 4) Define "medical examination", define conditions for this offer (in Belgium there are insufficient child neurologists and child psychiatrists to cover this offer)<br>5) Medisch onderzoek lijkt me vooral op indicatie te moeten gebeuren…de kinderen en jongeren met ASS die ik ken hebben zeker niet jaarlijks een medisch onderzoek nodig…daarnaast zijn er ook de medische consulten binnen CLB die meestal tweejaarlijks doorgaan (weliswaar met verschillende inhouden)…indien dit wordt meegenomen…wat zou dan moeten onderzocht worden? | |
| | **Diagnostic and therapeutic teams should collaborate closely. Professionals who** | y=10<br>n=0<br>na/?=1 | x | | 1) And also the educational teams !<br>2) But may be difficult to realise<br>3) Not always; Positive in the case of transition periods. | 4) Zou zeker beter moeten dan nu het geval is | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | KCE | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|
| **NICE GUIDELINE** | **HAS GUIDELINE** | | | | | |
| | | **Summary** | | **COMMENTS 1 - 3** | **COMMENTS 4-6** | **COMMENTS 7-9** |
| | **intervene only occasionally should consult the team.** | | | | | |
| | **Therapeutic teams should take part in the first information session with parents.** | y=9<br>n=1<br>na/?=1 | x | 1) Is this the first announcement of the diagnostic?<br>2) And also a professional more involved in education !<br>3) To discuss | 4) Lijkt me wat afhankelijk van situatie…ook niet altijd haalbaar. Eerste gesprek met ouders rond diagnose en mogelijkheden van ondersteuning moet ook nog ruimte laten voor 'vrije' keuze…als de 'therapeutische teams' er op dat moment al bij zijn is er eigenlijk geen keuze meer | |
| | **Transition periods e.g. transfer from one type of care/education to another or from childhood to adulthood require particular attention and should be prepared. Continuity of care should be assured.** | y=10<br>n=0<br>na/?=1 | x | 1) VERY IMPORTANT !<br>2) Zeker een belangrijk aandachtspunt; CLB heeft hierin een belangrijke opdracht, maar zeker voor leerlingen met ASS in gewoon onderwijs stellen we vast dat niet alle teams dit even goed kunnen opnemen. Samenwerking met BuO of andere instanties kan hier zeer zinvol zijn, maar goede afspraken zijn nodig rond wie wanneer moet ingeschakeld worden | | |
| | **Crisis situations require specific evaluation and intervention. Necessary information should be communicated among professionals, also in case hospitalization is inevitable. Specific education of professionals about crisis situations is necessary.** | y=10<br>n=0<br>na/?=1 | x | 1) Specialised centre for short term residence in crisis situations | | |

| STATEMENTS: ORGANISATION AND DELIVERY OF CARE | | KCE | | <70% yes | important comments | | | |
|---|---|---|---|---|---|---|---|---|
| NICE GUIDELINE | HAS GUIDELINE | | | | | | | |
| | | | Summary | | | COMMENTS 1 - 3 | COMMENTS 4-6 | COMMENTS 7-9 |
| | **Continuous education (every 2 to 3 years) is needed for all professionals.** | | y=10<br>n=0<br>na/?=1 | | x | 1) But at least yearly<br>2) Aangewezen maar realiseerbaarheid in diensten die 'breed' werken? ASS is niet de enige doelgroep waar CLB mee werkt…vraagt een herdenken van onze organisatie | | |
| | **Therapeutic teams should be accompanied by an external expert for debriefings once per month or per trimester.** | | y=7<br>n=2<br>na/?=2 | x | x | 1) not essential, is nice if it is possible<br>2) per trimester<br>3) Depends on type and multidisciplinarity of team: not always necessary | 4) Lijkt me een wat 'hoge' frequentie ; wat wordt bedoeld met een 'externe expert'? | |
| | **Professionals should not work in isolation but share experiences with peers or be supervised.** | | y=10<br>n=0<br>na/?=1 | | | | | |
| | **New professionals should be coached.** | | y=10<br>n=0<br>na/?=1 | | | | | |
| | **Awareness and support should be offered to professionals to prevent burn-out.** | | y=10<br>n=0<br>na/?=1 | | | | | |

## 5.2. Core features of autism (GDG 1 on 13-1-2014)

**Table 18 – Evidence and GDG discussion on domain 2: core features of autism**

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | | |
| **PSYCHOSOCIAL INTERVENTIONS** | | | | | **Summary** | | | **COMMENTS** |
| **Psychosocial, *overall autistic behaviour*** | Behavioural interventions<br>• ESDM | Insufficient evidence, no recommendation provided | <u>Under 4 yrs of age</u><br>• ABA<br>• ESDM<br>• ·TEACCH<br><u>Over 4 yrs of age</u><br>• Personalised programs | <br>grade B<br>grade B<br>grade C<br><br>expert consensus | y=9<br>n=0<br>na/?=2 | | x | 1. But not clear to distinguish the approaches<br>2. ABA has a grade B recommendation in the context of a 40 hours / week (which should be detailed).<br>-For ESDM refer to Pediatrics vol 125 n1, jan 1<br>3. The three methods suggested are partly related and overlap (at least ABA and TEACCH) but start from a totally different philosophy and way of looking at what is the basic deficit in autism. Thus, my appreciation of them differs on that basis: how is this captured? |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | KCE | <70% yes | important comments |
|---|---|---|---|---|---|---|
| NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | |
| | | | | | | 4. What's not exactly clear to me is whether the non-availability of studies on a specific method automatically leads to a non-recommendation? E.g. a specific method or intervention type may be very useful to caretakers, but if it isn't "picked up" by scientists and studied in terms of its effectiveness, it is not recommended? What are we rating then: the quality of the intervention method or the alertness of the scientist?<br>What is the status of "expert consensus": how is this rated?<br>My experience as a previous researcher and present clinician is that measuring the impact of a particular intervention method requires a very elaborate baseline description (which is seldom made) ànd long follow-up of the changes in behaviour. "Quick and short wins" are often easy to accomplish, but long term effectiveness is rare.<br>5. J'ai l'impression que la consigne n'est pas claire. En effet, par exemple, pour la première ligne; "psychosocial, overall autistic behavior", "Behavioral interventions", sur quoi dot porter notre accord (ou notre désaccord), sur les Interventions comportementales ? Sur les positions de NICE ou de la HAS ? Les interventions de NICE et de la HAS ne sont toutes les mêmes et lorsqu'elle sont les mêmes (ESDM), l'évaluation n'est pas la même ? Faut-il donner son accord de recommandation pour chaque modalité d'intervention (ABA, TEACCH, ESDM, …) ? |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | |
| | | | | | | | 6. Which recommendation will be made by the KCE? It's of course difficult to have an RCT (used in medications!) for the educational interventions Is it appropriate to write "no recommendation" even if the evidence is low. "Low" is better than "no recommendation<br>7. Il n'est pas toujours aisé de bien comprendre le tableaux car NICE et HAS ne mettent pas ensemble les mêmes points.<br>Il n'est pas facile de compartimenter les interventions (surtout si elles sont comportementales ou développementales) en fonctions des domaines dans lesquels des progrès sont constatés.<br>Je m'étonne de ne pas voir de mention dans le rapport sur ce qui est appelé « alternative management strategies » ; ni de « réponses » concernant vos questions de recherche ; notamment quant aux recommandations en fonction de la sévérité du trouble et/ou de la comorbidité ; ou de sous-groupes (immigrants, enfants avec des régressions,…).<br>Il est sans doute utile de préciser si le « should not be used » implique la notion « do not use » telle qu'elle est précisée dans le rapport NICE. |
| **Psychosocial, *overall autistic behaviour*** | Educational interventions<br>• ESDM<br>• LEAP<br>• COMPASS | Insufficient evidence, no recommendation provided | | | y=7<br>n=0<br>na/?=4 | x | x | 1. Pas d'expérience avec: ESDM, COMPASS et LEAP<br>2. Globalement d'accord avec les interventions éducatives mais pas de connaissance de Leap et compass<br>3. Randomized control trial exists for LEAP. So there is some level of evidence. Needs to be discussed in group |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | | | |
| | | | | | | | | | 4. Ondersteuning nodig, maar oog voor gradaties…niet alles of niets op basis van diagnose |
| **Psychosocial, *overall autistic behaviour*** | Parent training | Insufficient evidence, no recommendation provided | | | | y=6<br>n=2<br>na/?=3 | x | x | 1. Starting from my professional experience: parent training is crucial as part of an overall approach – it will not work as such.<br>2. Notre experience de la formation de parent est positive<br>3. See above. Parent Training is essential! Even if the evidence is insufficient<br>4. Psychoeducation Groups for parents and and a Guidance at home<br>5. Parent training is a core feature of ESDM (see above) |
| **Psychosocial, *overall autistic behaviour*** | | | <u>Asperger syndrome</u><br>• TCC<br>• Role play<br>• Conversation groups<br>• Individual psychotherapy | <br>grade B<br>grade C<br>expert consensus<br>expert consensus | | y=7<br>n=0<br>na/?=4 | x | x | 1. Too generic ! What individual Psychotherapies are recommended?<br>2. TCC = CBT in English- “Asperger syndrome is no longer a category in DSM-5<br>3. Faut-il encore parler du syndrome d’Asperger (cfr DSM V)<br>4. We did not have the time to check |
| **Psychosocial, *overall autistic behaviour*** | Social-communication intervention<br>• Child’s Talk | Insufficient evidence, no recommendation provided | | | | y=4<br>n=0<br>na/?=7 | x | | Je en connais pas cetet strategies - Pour quel niveau d'enfant |
| **Psychosocial, *overall autistic behaviour*** | | | Psychoanalysis, institutional psychotherapy | No consensus | To DISCUSS | y=2<br>n=5<br>na/?=4 | x | x | 1. In my experience: no effect.<br>2. Psychoanalysis and institutional psychotherapy should be distinguished Psychoanalysis should be “not recommended”. “No<br>3. consensus” is accepted for institutional psychotherapy<br>4. I agree with the no consensus<br>5. Should at least be unsufficient evidence, better: not recommended |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | | |
| | | | | | | | | 6. CBT/BIOPSYCHOSOCIAL MODEL<br>7. First to discuss before taking a decision |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Animal-based intervention<br>• horseback riding | Insufficient evidence, no recommendation provided | | | y=8<br>n=1<br>na/?=2 | | x | 1. But not harmful<br>2. Peut être profitable an terme d'activités ou de contexte à une intervention<br>3. Utilité d'une approche "assistée par l'animal" |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Arts-based intervention<br>• relational music therapy | Insufficient evidence, no recommendation provided | | | y=7<br>n=1<br>na/?=3 | x | | 1. But not harmful<br>2. Peut être profitable an terme d'activités ou de contexte à une intervention |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | | | Speech therapy<br>Early global intervention | expert consensus<br>grade B | y=10<br>n=0<br>na/?=1 | | x | 1. Effect of speech therapy in ASD + language impairment ???<br>2. I did not find back the studie grade B qualification refers too; requires discusion |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Behavioural interventions<br>• ESDM<br>• P-ESDM<br>• reciprocal imitation training | Insufficient evidence, no recommendation provided | | | y=6<br>n=0<br>na/?=5 | x | | 1. Pas d'expérience |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Cognitive interventions<br>• ERT<br>• FRT<br>• ToM | Insufficient evidence, no recommendation provided | | | y=7<br>n=0<br>na/?=4 | x | x | 1. Have only temporary, context-specific effect.<br>2. ToM: is it a therapy (rather theory or deficit)<br>3. Interventions cognitives utiles, mais pourquoi exlcure dans le rapport l'approche Feuerstein? |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Educational interventions<br>• LEAP<br>• TeachTown: Basics + IBI | Insufficient evidence, no recommendation provided | | | y=6<br>n=0<br>na/?=5 | x | | 1. Pas d'expérience avec : LEAP TeachTown:Basics + IBI |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE RECOMMEN-DATION | | | | |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Parent training | Insufficient evidence, no recommendation provided | | y=8<br>n=0<br>na/?=3 | | | 1. see comment above<br>2. Notre experience de la formation de parent est positive<br>3. See comment on ESDM |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Picture Exchange Communication System Training<br>• ACC | Insufficient evidence, no recommendation provided | | y=9<br>n=0<br>na/?=2 | | | 1. Very useful in the care of people.<br>2. Notre experience est poristive |
| **Psychosocial, *impaired reciprocal social communication and interaction*** | Social-communication Interventions<br>• EBI/EIBI + joint attention training<br>• LEGO therapy<br>• social skills groups | Recommended*<br>- | | y=9<br>n=0<br>na/?=2 | | x | 1. No idea on the LEGO-therapy. As to social skills groups: ? Long term effectiveness?<br>2. LEGO therapy: used in Belgium? If not: why mentioned here?; Pas d'expérience avec : LEGO therapy<br>3. But Grade B in terms of HAS<br>4. y pour EIBI et les groups d'habiletés sociales (pas de connaissance de la legotherapy)<br>5. Requires a better descerption of what falls exactly under the terminology of EBI/EIBI<br>6. social skills groups |
| **Psychosocial, *restricted interests and rigid and repetitive behaviours*** | Behavioural intervention<br>• ESDM<br>• P-ESDM | Insufficient evidence, no recommendation provided | | y=6<br>n=0<br>na/?=5 | x | | 1. Pas d'expérience |
| **Psychosocial, *restricted interests and rigid and repetitive behaviours*** | Cognitive intervention<br>• enhanced ERT | Insufficient evidence, no recommendation provided | | y=5<br>n=0<br>na/?=6 | x | | 1. Pas d'expérience |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | | |
| **Psychosocial, *restricted interests and rigid and repetitive behaviours*** | Parent Training | Insufficient evidence, no recommendation provided | | | y=8<br>n=0<br>na/?=3 | | | 1. see comment above<br>2. Notre experience de la formation de parent est positive |
| **Psychosocial, *restricted interests and rigid and repetitive behaviours*** | Social-communication intervention<br>• PACT | Insufficient evidence, no recommendation provided | | | y=5<br>n=0<br>na/?=6 | x | x | 1. Pas d'expérience avec PACT<br>2. One study shows benefits!<br>J Autism Dev Disord<br>DOI 10.1007/s10803-013-1874-z |
| **Psychosocial,*cognitive domain*** | | | early global intervention<br>stimulate child's interest<br>speech therapy, physical therapy, psychotherapy<br>educational support<br>caretakers' collaboration<br>structured environement | grade B if initiated before 4 yrs of age | y=9<br>n=0<br>na/?=2 | | x | 1. Too generic See above<br>2. What is the concrete Intervention in this recommendation?<br>3. To discuss psychomotricité relationnelle type "Au couturier" ; often used in the french talking part of Belgium |
| **Psychosocial,*sensori-motor domain*** | | | physical therapy, ergotherapy | expert consensus | y=9<br>n=1<br>na/?=1 | | x | 1. To specify which kind of physical therapy<br>2. Only HAS experts?<br>3. Indien problemen op dit vlak |
| **Psychosocial, *sensori-motor domain*** | | | <u>Not therapeutic but beneficial for personal and social enjoyment:</u><br>physical activity<br>musical therapy<br>therapy involving animals | expert consensus | y=7<br>n=1<br>na/?=3 | x | x | 1. What about sensory integration training/ therarpy? |
| **PHARMACOLOGICAL INTERVENTIONS**d | | | | | 5 persons declared not specialized | | | |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | <70% yes | important comments | |
|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | | |
| **Pharmacological, *overall autistic behaviour*** | Pharmacological interventions<br>• anticonvulsants<br>• antidepressants<br>• antipsychotics (with or without antihistamines)<br>• SNRIs | Not recommended*<br>Not recommended*<br>Not recommended*<br>Insufficient evidence, no recommendation provided | • antipsychotics<br>• SSRI's<br>• dopamine reuptake inhibitors<br>• SNRI's<br>• antiepileptics. | Not recommended | y=4<br>n=1<br>na/?=1 | x | x | 1. Antipsychotics are commonly used today in Belgium for overall autistic behaviour<br>2. I am not specialized in medications and in biomedical interventions<br>3. Antipsychotics like risperdal and ariprazole were described as slight having a slight positive role on risperidone (2 trials) or aripiprazole (1 trial) on compulsions<br>- Discuss the positive role of antiepileptics and antipsychotics on side symptoms of ASD<br>4. Discussion |
| **Pharmacological, *impaired reciprocal social communication and interaction*** | Pharmacological intervention<br>• antioxidants | Insufficient evidence, no recommendation provided<br>- | | | y=6<br>n=0 | | | |
| **Pharmacological, *restricted interests and rigid and repetitive behaviours*** | Pharmacological interventions<br>• antidepressants<br>• antioxidants | Not recommended*<br>-<br>- | | | y=6<br>n=0 | | x | 1. Depending on commorbidity<br>2. antidepressants |
| **BIOMEDICAL INTERVENTIONS** | | | | | 5 persons declared not specialized | | | |
| **Biomedical, *overall autistic behaviour*** | Complementary interventions<br>• acupressure<br>• acupuncture<br>• electro-acupuncture<br>• Qigong massage | Insufficient evidence, no recommendation provided | | | y=6<br>n=0 | | | |
| **Biomedical, *overall autistic behaviour*** | Hormone therapy<br>• porcine secretin | Not recommended* | Hormone therapy<br>• secretin | | y=6<br>n=0 | | | Melatonin for sleep Disturbances ? |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | KCE | <70% yes | important comments |
|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | |
| | • synthetic porcine secretin<br>• synthetic human secretin | | • melatonin | Not recommended*<br>OK for sleep disturbances | | | |
| **Biomedical, *overall autistic behaviour*** | Medical procedures<br>• chelation<br>• HBOT | Not recommended* | Medical procedures<br>• chelation<br>• immunotherapy | Not recommended* | y=6<br>n=0 | | |
| **Biomedical, *overall autistic behaviour*** | Nutritional interventions<br>• multivitamin + mineral supplement<br>• L-carnosine/L carnitine<br>• omega-3 fatty acid<br>• gluten – and casein free diet | Insufficient evidence<br>Insufficient evidence<br>Insufficient evidence<br>Not recommended* | Nutritional interventions<br>• multivitamin + mineral supplement<br>• omega-3 fatty acid<br>• gluten – and casein free diet | Not recommended* | y=6<br>n=0 | | Gluten-free diet is sometimes used in Belgium today |
| **Biomedical, *overall autistic behaviour*** | Sensory interventions<br>• neurofeedback<br>• auditory integration training | Insufficient evidence, no recommendation provided | Sensory interventions<br>• auditory integration training | Not recommended | y=5<br>n=0<br>na/?=1 | | |
| **Biomedical, *overall autistic behaviour*** | | | Other drugs<br>• antibiotics<br>• antifugals<br>• dextrometorphan<br>• famotidine<br>• amantadine<br>• benzodiazepines<br>• antihistaminics | Not recommended | y=6<br>n=0 | | |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | KCE | <70% yes | important comments |
|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE RECOMMEN-DATION | | | |
| **Biomedical, *impaired reciprocal social communication and interaction*** | Complementary interventions<br>• electro-acupuncture | Insufficient evidence, no recommendation provided | | y=6<br>n=0 | | |
| **Biomedical, *impaired reciprocal social communication and interaction*** | Hormone therapy<br>• porcine secretin<br>• synthetic porcine secretin | Not recommended* | | y=6<br>n=0 | | |
| **Biomedical, *impaired reciprocal social communication and interaction*** | Medical procedure<br>• chelation<br>• HBOT | Not recommended* | | y=6<br>n=0 | | |
| **Biomedical, *impaired reciprocal social communication and interaction*** | Nutritional interventions<br>• multivitamin + mineral supplement<br>• L-carnosine/ L-carnitine<br>• omega-3 fatty acid<br>• gluten – and casein free diet | Insufficient evidence<br>Insufficient evidence<br>Insufficient evidence<br>Not recommended* | | y=6<br>n=0 | | See above |
| **Biomedical, *impaired reciprocal social communication and interaction*** | Sensory intervention<br>• neurofeedback | Insufficient evidence, no recommendation provided | | y=6<br>n=0 | | |
| **Biomedical, *restricted interests and rigid and repetitive behaviours*** | Hormone therapy<br>• porcine secretin<br>• synthetic porcine secretin | Not recommended* | | y=6<br>n=0 | | |

| STATEMENTS: TREATMENT of CORE FEATURES of AUTISM | | | | | KCE | <70% yes | important comments |
|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, CORE AUTISM FEATURES | RECOMMENDATION | HAS GUIDELINE | RECOMMEN-DATION | | | |
| **Biomedical, *restricted interests and rigid and repetitive behaviours*** | Medical procedures<br>• chelation<br>• HBOT | Not recommended* | | | y=6<br>n=0 | | |
| **Biomedical, *restricted interests and rigid and repetitive behaviours*** | Motor intervention<br>• Kata exercise training | Insufficient evidence, no recommendation provided | | | y=6<br>n=0 | | |
| **Biomedical, *restricted interests and rigid and repetitive behaviours*** | • L-carnosine/L-carnitine<br>• gluten – and casein free diet | Insufficient evidence<br>Not recommended* | | | y=6<br>n=0 | | |
| **Biomedical, *restricted interests and rigid and repetitive behaviours*** | Sensory intervention<br>• neurofeedback | Insufficient evidence, no recommendation provided | | | y=6<br>n=0 | | |
| **Additional Comments** | | | | | | | |

*Legend (column G-Q):*
*y=yes n=no ? =don't know- don't understand na=no answer*

## 5.3. Behaviour that challenges (GDG 2 on 24-2-2014)

### Table 19 – Evidence and discussion on domain 3: behaviour that challenges

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES | NICE RECOMMENDATION | HAS GUIDELINE | HAS RECOMMENDATION | GDG yes; no; na/?; not specialised | | COMMENTS | |
| **PSYCHOSOCIAL INTERVENTIONS** | | | | | | | | |
| **First-line treatment:** | If no coexisting mental health or behavioural problem, 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** (informed by a **functional assessment** of behaviour) as a first-line treatment | Recommended (mainly based on expert consensus) | expert opinion: In case of challenging behaviour that is dangerous for the child or the environment: use psycho-educational – behavioural techniques 'CBT' | Expert consensus: recommended | Yes<br>No<br>NA<br>?<br>Not specialized | **10** | • yes for NICE guideline, but HAS guideline (CBT) is far too specific and even unrealistic in the face of challenging behaviour.<br>• All those points are not specific for autism | • 1) 2) 3) 4) 5) 6) 7) 8)yes for NICE guideline, but HAS guideline (CBT) is far too specific and even unrealistic in the face of challenging behaviour.<br>• 1) 2) 3) 4) 5) 6) All those points are not specific for autism7) 8) |
| **First-line treatment:** ***Functional assessment*** | The functional assessment should identify:<br>• factors that appear to trigger the behaviour<br>• ·patterns of behaviour<br>• the needs that the child or young person is attempting to meet by performing the behaviour<br>• the consequences of the behaviour (that is, the reinforcement received as a result of the behaviour). | Recommended (mainly based on expert consensus) | Expert consensus:<br>• Assess comorbidity<br>• Identify sources of physical pain<br>• Identify triggers | Expert consensus: recommended | Yes<br>No<br>NA<br>?<br>Not specialized<br>Yes<br>No<br>NA<br>?<br>Not specialized | **8**<br><br>**2**<br><br>**10** | 1) the behavior problem has a communication function and the professionnal has to understand what the person tends to communicate2) Importance of sources of physical pain (a medical - somatic factors - check sould be a part of functionnal assessment 3) Fysical examination is crucial as a first step to be taken! | 1) 2) 3) 4) the behavior problem has a communication function and the professionnal has to understand what the person tends to communicate.5) 6) Importance of sources of physical pain (a medical - somatic factors - check sould be a part of functionnal assessment)7) |
| **First-line treatment: Psychosocial interventions** | Psychosocial interventions for behaviour that challenges should include: | Recommended (mainly based on expert consensus) | Expert opinion: Isolation chamber<br>Expert opinion: Packaging technique | Use only in exceptional cases | Yes<br>No<br>NA<br>? | 10<br><br>**6**<br>**1** | The strategies have to be positive (no use of aversive stimuli, mainly as consequences) | The strategies have to be positive (no use of aversive stimuli, mainly as consequences) |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | | |
|---|---|---|---|---|---|---|---|
| **NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES** | **NICE RECOMMENDATION** | **HAS GUIDELINE** | **HAS RECOMMENDATION** | **GDG yes; no; na/?; not specialised** | | **COMMENTS** | |
| • clearly identified target behaviour<br>• ·a focus on outcomes that are linked to quality of life<br>• assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour<br>• a clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person<br>• a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time)<br>• a systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met | | | Ensure continued support and respect for the child<br>Recommended not to use | Not specializedYes<br>No<br>NA<br>?<br>Not specialized<br>Yes<br>No<br>NA<br>?<br>Not specialized<br>Yes<br>No<br>NA<br>?<br>Not specialized | **2**<br>**1**<br>**(discuss)**<br>**2**<br><br>**8**<br>**7**<br><br>**2**<br>**1** | 1) See recommandations of "centre pour l'égalité des chances" Belgium-joined document<br>2) The use of an isolation chamber can be a useful. To give someone a “time-out” is often crucial in dealing with challenging behaviour, but this should seldom lead to isolation chambers.<br>3) to use only after multiple other possibilities are offered to the child to regain control are unsuccessful<br><br>1) Packing is forbidden by AWIPH in the institutions that they finance (letter 12/02/23 A, Baudine)<br>2) What is meant here? Fixation? | 1) 2) 3) 4) 5) 6) See recommandations of "centre pour l'égalité des chances" Belgium-joined document7) 8)<br>1) Packing is forbidden by AWIPH in the institutions that they finance (letter 12/02/23 A, Baudine)2) 3) 4) 5) 6) Recommended not to use7) 8) |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | | |
|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES | NICE RECOMMENDATION | HAS GUIDELINE | HAS RECOMMENDATION | GDG yes; no; na/?; not specialised | | COMMENTS |
| | • ·consistent application in all areas of the child or young person's environment (for example, at home and at school)<br>• agreement among parents, carers and professionals in all settings about how to implement the intervention. | | | | | | |
| **PHARMACOLOGICAL INTERVENTIONS** | | | | | | | |
| | 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 | Recommended | | | Yes<br>No<br>NA<br>?<br>Not specialized | **7**<br><br><br>**2**<br>**1** | Does it mean that antipsychotic medication are efficient on challenging behavior ? |
| | • Antipsychotic medication should be initially prescribed and monitored by a paediatrician or psychiatrist who should:<br>• identify the target behaviour<br>• decide on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact | Recommended (mainly based on expert consensus) | | | Yes<br>No<br>NA<br>?<br>Not specialized | **7**<br><br>**1**<br><br>**2** | 1) Of course<br>2) Before the start of the medication a bloodanalysis and cardiologic screening should be performed to exclude a metabolical, endocrinological or cardial risk.<br>prescribed and monitored by a childpsychiatrist or a pediatric neurologist or a neuropediatrician | 1) 2) 3) 4) 5) 6) Of course7) 8) |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | |
|---|---|---|---|---|---|---|
| **NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES** | **NICE RECOMMENDATION** | **HAS GUIDELINE** | **HAS RECOMMENDATION** | **GDG yes; no; na/?; not specialised** | **COMMENTS** | |
| • review the effectiveness and any side effects of the medication after 3–4 weeks<br>• stop treatment if there is no indication of a clinically important response at 6 weeks. | | | | | | |
| If antipsychotic medication is prescribed:<br>• start with a low dose<br>• use the minimum effective dose needed<br>• regularly review the benefits of the antipsychotic medication and any adverse events. | Recommended (based on evidence and expert consensus) | | | Yes **9**<br>No<br>NA<br>?<br>Not specialized **1** | Of course | 1) 2) 3) 4) 5) 6) Of course7) 8) |
| When choosing antipsychotic medication, take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate) and response to previous treatment with an antipsychotic. | Recommended (based on evidence and expert consensus) | | | Yes **9**<br>No<br>NA<br>?<br>Not specialized **1** | a written information should be given to parents | 1) 2) 3) 4) 5) 6) a written information should be given to parents7) 8) |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | | |
|---|---|---|---|---|---|---|---|
| **NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES** | **NICE RECOMMENDATION** | **HAS GUIDELINE** | **HAS RECOMMENDATION** | **GDG yes; no; na/?; not specialised** | | **COMMENTS** | |
| When prescribing is transferred to primary or community care, the specialist should give clear guidance to the practitioner who will be responsible for continued prescribing about:<br>• the selection of target behaviours<br>• monitoring of beneficial and side effects<br>• the potential for minimally effective dosing<br>• the proposed duration of treatment<br>• plans for stopping treatment. | Recommended (mainly based on expert consensus) | RCT with positive outcome on irritability, stereotypic behaviour and hyperactivity<br>· haloperidol vs placebo (n=126)<br>· risperidone vs placebo and risperidine vs haloperidol (n=89)<br>· aripiprazole vs placebo (n=213)<br>RCT with positive outcome on hyperactivity<br>· methylphenidate vs placebo | Expert consensus: Recommend as second line and temporary treatment<br><br>Expert consensus: Recommend as second line and temporary treatment | Yes<br>No<br>NA<br>?<br>Not specialized<br><br>Yes<br>No<br>NA<br>?<br>Not specialized<br><br>Yes<br>No<br>NA<br>?<br>Not specialized | 8 (1 partially)<br>1<br><br>1<br><br>**4**<br><br>**1**<br><br>**5**<br><br>**6**<br><br>**4** | 1) the question is whether such a transfer is advisable,2) transferring to primary care should also involve a scheme for follow-up by specialised care. Patients on antipsychotics should not be left to primary care alone, due to lack of experience in many cases<br>3) In my experience the specialist should always stay in charge of the treatment: the MP can't take over this role! The effect of antipsychotic medication on people with autism is often so idiosyncratic it should be monitored by an expert.<br>4) Once in a year there should be an extensive control bya childpsychiatrist or a pediatric neurologist, was RCT performed during episodes of challenging behaviour? Or only when the named symptoms occured?<br>We almost never prescribe haldol in the context of ASD<br>What are the results concerning the direct comparison between risperidone and haldol? | 1) 2) 3) the question is whether such a transfer is advisable4) 5) 6) 7) 8)transferring to primary care should also involve a scheme for follow-up by specialised care. Patients on antipsychotics should not be left to primary care alone, due to lack of experience in many cases.<br>1) 2) 3) 4) 5) 6) 7) 8)was RCT performed during episodes of challenging behaviour? Or only when the named symptoms occured?<br>1) 2) What are the results concerning the direct comparison between risperidone and haldol? Does Risperidone come as first line followed by haloperidol3) 4) 5) 6) 7) 8)<br>1) 2) 3) 4) 5) 6) 7) 8)only in the presence of ADHD: hyperactivity may signify many different things in person with ASD |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | | | |
|---|---|---|---|---|---|---|---|
| | NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES | NICE RECOMMENDATION | HAS GUIDELINE | HAS RECOMMENDATION | GDG yes; no; na/?; not specialised | | COMMENTS |
| | | | | | | | Does Risperidone come as first line followed by haloperidol<br><br>only in the presence of ADHD: hyperactivity may signify many different things in person with ASD |
| **BIOMEDICAL INTERVENTIONS** | | | | | | | |
| | Trials included massage, multivitamin and mineral supplement, electro-acupuncture, hormone treatment (secretin), medical procedures (HBOT and DMSA), nutritional and sensory interventions | Insufficient evidence, no recommendations provided | | | Yes<br>No<br>NA<br>?<br>Not specialized | **6**<br>**1**<br><br><br>**2**<br>**1** | 1) are those interventions specific for the treatment of challenging behavior ? 2) these practices are not harmful, they generaly cost a lot of monney without reimbursment to parents who, generaly on the base of false/and or misleading information should do anything for there child to be sure that they shouldn't need to blame thereself to not have tried everything. It's not proven that these practices are not harmful, they generaly cost a lot of monney without reimbursment to parents who, generaly on the base of false/and or misleading information should do anything for there child to be sure that they shouldn't need to blame |

| STATEMENTS: BEHAVIOUR THAT CHALLENGES | | | | | |
|---|---|---|---|---|---|
| NICE GUIDELINE, BEHAVIOUR THAT CHALLENGES | NICE RECOMMENDATION | HAS GUIDELINE | HAS RECOMMENDATION | GDG yes; no; na/?; not specialised | COMMENTS |
| | | | | | thereself to not have tried everything. After every expensive 'therapy' generaly follows the desillusion what makes that these already vulnarable parents |

*Legend (column Summary of GDG scores): y=yes / n=no / ? =don't know- don't understand / na=no answer / Not specialised = stated that not specialized in medications and in biomedical intervention*

*Associated features of autism and coexisting conditions (GDG 3 on 31-3-2014)*

## 5.4. Associated features of autism and coexisiting conditions (GDG 3 on 31-3-2014)

### Table 20 – Evidence and discussion on domain 4: associated features of autism and coexisting conditions

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| NICE guideline | NICE Recommendation | HAS guideline | HAS Recommendation | GDG Yes ; No ; Na/? ; Not specialised | Comments |
| **1. Intervention domain : *Impairments in adaptive behaviour*** | | | | | |
| Psychosocial interventions | | | | | |
| Behavioural interventions<br>• EIBI or EBI vs. TAU<br>• EIBI vs. Parent Training<br>• Home-based EBI vs. Centre-based EBI | Insufficient evidence, no recommendation provided | | | 8 Yes, 1 NA | |
| Cognitive-behavioural interventions<br>• CBT vs. Wait-list | Insufficient evidence, no recommendation provided | | | 8 Yes, 1 NA | |
| Parent training<br>• Parent training vs. TAU<br>• Combined Parent training and Early Intervention Programme vs. Early Intervention Programme alone | Insufficient evidence, no recommendation provided | | | 8 Yes, 1 NA | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| • Parent and day-care staff training vs. Standard day-care<br>• Combined parent training and anti-psychotic vs. antipsychotic alone | | | | | |
| Social-Communication interventions<br>• Caregiver-mediated social communication intervention vs. TAU<br>• Social skills group vs. TAU<br>• LEGO therapy vs. SULP | Insufficient evidence, no recommendation provided | | | 8 Yes, 1 NA | |
| Pharmacological interventions | | | | | |
| • ·Aripiprazole vs. placebo | Insufficient evidence, no recommendation provided | | | 5 Yes, 4 NA | |
| Biomedical interventions | | | | | |
| Complementary interventions<br>• Acupuncture/electroacupuncture vs. Sham<br>• Acupuncture/electroacupuncture and educational programme vs. educational programme<br>Hormone interventions<br>• Secretin vs. placebo<br>Medical procedure interventions<br>• Long-term chelation (7 rounds of DMSA) vs. Short-term chelation (1 round of DMSA and 6 rounds of placebo)<br>• HBOT vs. attention-placebo<br>Nutritional interventions<br>• Omega-3 fatty acids vs. placebo<br>• Omega-3 fatty acids vs. healthy diet control<br>• Gluten-free and casein-free diet vs. TAU | Insufficient evidence, no recommendation provided | | | 6 Yes, 3 NA | |
| **2.Intervention domain : *Speech and language problems*** | | | | | |
| Psychosocial interventions | | | | | |
| ACC interventions<br>• PECS vs. TAU | Insufficient evidence, no recommendation provided. | | | 5 Yes, 3 ?, 1 Res recomm | research recommendation seems indicated - The effectiveness of |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| • PECS vs. RPMT | However, the evidence is promising and therefore a research recommendation is provided (see text). | | | 4 Yes, 5 ? | AAC should be the focus of further research as clinical practice does reveal positive outcome<br>Ne pourrions nous pas affirmer, sur base d'un consensus d'experts, l'intérêt de mettre en place le PECS pour favoriser le développement de la communication ? I would also underscore the "research recommendation" |
| | | • ·PECS<br>• ·socially engaged imitation, engaged imitation, joint attention and affect sharing<br>• joint attention vs play interventions<br>• Denver model vs PROMPT<br>• Denver model vs RIT | Personalized project should:<br>• include functional objectives in the field of verbal or non-verbal communication<br>• be implemented in collaboration with parents and other care providers<br>• ·be implemented even before certain diagnosis (grade C). | 7 Yes, 2 ? | underscore that scientific evidence is still (very) limited |
| Arts-based interventions<br>• Music therapy vs. TAU | Insufficient evidence, no recommendation provided | | | 8 yes, 1 ? | not harmful |
| Behavioural interventions<br>• EIBI vs. TAU<br>• EBI vs. TAU<br>• EIBI vs. Parent training<br>• Home-based EBI vs. Centre-based EBI | Insufficient evidence, no recommendation provided | | | 7 Yes, 2 ? | |
| Educational interventions<br>• TeachTown + IBI vs. IBI (only) | Insufficient evidence, no recommendation provided | | | 5 Yes, 1 NA, 3 ? | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| • LEAP training vs. Manual-only control | However based on promising results of the LEAP intervention research recommendation provided. | | | | |
| Parent training<br>• Parent Training vs. TAU<br>• Parent and day-care staff training vs. Standard day-care | Insufficient evidence, no recommendation provided | | | 7 Yes, 2 ? | In general behavioral therapies benefit from involvement of families to ensure continuity and consistency of practices |
| Social-Communication interventions<br>• Caregiver-mediated social communication intervention vs. TAU<br>• Social skills group vs. TAU<br>• Joint attention training and EBI/EIBI vs. EBI/EIBI only | Insufficient evidence, no recommendation provided | • ·socially engaged imitation, engaged imitation, joint attention and affect sharing | The development of functional communication requires:<br>• Individualized relationship<br>• Specific techniques implemented for the development of joint attention through simulation introducing progressive changes (grade C)<br>• endorsement by parents and caretakers in daily live.<br>Recommended interventions are:<br>• Speech therapy sessions (expert opinion)<br>• Schedule TBD by needs, constraints and priorities: for <6yrs old 2-4 wks | 6 yes,1 NO, 2 ?<br>4 Yes, 5 ?<br>4 Yes, 5 ?<br>3 Yes, 6 ?<br>3 Yes, 6 ?<br>2 Yes, 1 NA, 6 ? | research recommendation should be considered I agree with most of this section, but not with the part "speech therapy" sessions in HAS, because this is not too unspecific. Goals of speech therapy should be mentioned.<br>Importance de ne pas exclure les enfants ayant un QI insuffisant. Eux aussi peuvent tirer bénéfice de la logopédie pour le travail de la communication , notamment dans ses aspects non verbaux |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | | | • Educational, behavioural and individualized intervention (AAC) implemented within the framework of early, global and coordinated (expert opinion) | 4 Yes, 5 ? | |
| | | | • Provide training for parents | | |
| | | | • Do NOT exclude children >6yrs old even if not verbal | | |
| | | | • Provide excercices at school | 4 Yes, 5 ? | |
| | | | | 4 Yes, 5 ? | |
| | | | | 4 Yes, 5 ? | |
| | | • Based on one SR | It is recommended not to use the techniques of 'facilitated communication' | 7 Yes, 2 ? | note: this depends on what is meant by "facilitated communication": if it means helping hand of person with autism, than I agree not to recommend; if it more broadly also includes e.g. aspects of TEACCH, then I do not agree not to recommend. Please, specify. |
| Pharmacological interventions | | | | | |
| No evidence found | No recommendation | | | 3 Yes, 1 No, 3 NA, 1? | |
| Biomedical interventions | | | | | |
| Complementary interventions<br>• Acupuncture/acupressure and language therapy vs. Language therapy alone | Insufficient evidence, no recommendation provided | | | 3 Yes,3 NA, 3 ?<br>4 Yes, 5 ? | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| • Acupuncture/electroacupuncture vs. Sham acupuncture/ electroacupuncture | | | | | |
| Hormone interventions<br>• Secretin vs. Placebo | Insufficient evidence, no recommendation provided | | | 4 Yes, 3 NA, 2 ? | POSSIBLY HARMFULL: NOT RECOMMENDED |
| Medical procedure interventions<br>• Long-term chelation (7 rounds of DMSA) vs. Short-term chelation (1 round of DMSA and six rounds of placebo)<br>• HBOT vs. attention-placebo | Insufficient evidence, no recommendation provided | | | 3 Yes, 2 NA, 4 ?<br>3 Yes, 1 NA, 5 ? | recommendation not to use<br>POSSIBLY HARMFULL: NOT RECOMMENDED |
| Nutritional interventions<br>• Omega-3 fatty acids vs. Placebo<br>• Omega-3 fatty acids vs. healthy diet control<br>• Multivitamin/mineral spupplement vs. Placebo<br>• L-carnosine supplement vs. Placebo | Insufficient evidence, no recommendation provided | | | 3 Yes, 2 NA, 4 ?<br>3 Yes, 1 NA, 5 ? | |
| Sensory interventions<br>• Auditory integration training vs. Attention-placebo | Do <u>not</u> use auditory integration training | | | 2 Yes, 1 NA, 6 ? | |
| Sensory interventions<br>• ·Neuro-feedback vs. TAU | Do <u>not</u> use neurofeedback to manage speech and language problems in children and young people with autism | | | 4 Yes, 1 NA, 4 ? | |
| **3. Intervention domain : *IQ, academic skills and learning*** | | | | | |
| Psychosocial interventions | | | | | |
| Behavioural interventions<br>• EIBI or EBI vs. TAU<br>• EIBI vs. Parent training | Insufficient evidence, no recommendation provided | | | 4 Yes, 1 NA, 4 ? | promising results |
| Educational interventions<br>• LEAP training vs. Manual-only control | Insufficient evidence, no recommendation provided. However, promising results so research recommendation provided. | | | 4 Yes, 2 NA, 3?<br>3 Yes, 6? | agree with research recommendation |
| Parent training<br>• Parent Training vs. TAU | Insufficient evidence, no recommendation provided | | | 5 Yes, 1 NA, 3 ? | promising results, Parents training and parent involvement should be encouraged |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| • Combined parent training and early intervention centre programme vs. Early intervention centre programme | | | | | |
| Social-Communication interventions<br>• Caregiver-mediated social communication intervention vs. TAU<br>• Joint attention training and EIBI vs. EIBI | Insufficient evidence, no recommendation provided | | | 4 Yes, 1 NA, 4 ? | |
| | | Partial or total school integration<br>• Expert opinion | Offer full-time schooling in mainstream or adapted environment. | 5 Yes, 4 ?<br>5 Yes, 4 ? | See below-is not a specific intervention, depends on contextual factors<br>promising results |
| | | Partial or total school integration<br>• Expert opinion | Recommended:<br>• Progressively increase time at school<br>• Provide mentor with training in autism<br>• Inform peers if child/adolescent and parents agree | 4 yes, 5 ? | Should be recommended with adequate support-idem |
| | | Partial or total school integration<br>• ·Expert opinion | • adolescent may benefit from coaching during traineeship or jobsearch | | |
| Pharmacological interventions | | | | | |
| Pharmacological interventions<br>• Risperidone vs. Placebo | Insufficient evidence, no recommendation provided | | | 4 Yes, 1 NA, 4 ? | |
| Biomedical interventions | | | | | |
| Complementary interventions<br>• Acupuncture/electroacupuncture vs. Sham acupuncture/ electroacupuncture<br>Hormone interventions<br>• ·Secretin vs. Placebo<br>Nutritional interventions<br>• Multivitamin/mineral supplement vs. Placebo | Insufficient evidence, no recommendation provided (for all listed intervention types) | | | 4 Yes, 1 NA, 4 ?<br>5 Yes, 1 NA<br>5 Yes, 1 NA<br><br>POSSIBLY HARMFULL: NOT RECOMMENDED | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| Sensory interventions<br>• Auditory integration training vs. Attention-placebo | | | | | |
| **4. Intervention domain : *Sensory sensitivities*** | | | | | |
| Psychosocial interventions | | | | | |
| Animal-based interventions<br>• Horseback riding vs. Waitlist control | Insufficient evidence, no recommendation provided | Animal based therapies | Insufficient evidence, no recommendation provided | 7 Yes, 1 NA, 1? | general: is core symptom in DSM-5 |
| Educational interventions<br>• Combined TeachTown and IBI vs. IBI (only) | Insufficient evidence, no recommendation provided | • Expert opinion | Visual impairment should be treated adequately | 7 Yes, 2? | |
| | | • Expert opinion | Significant hypersensitivity should be attenuated or modulated, and the environment adjusted | 8 Yes, 1? | |
| | | Hearing filters<br>• Expert opinion | In case of hyperacusis auditory filters may be proposed | 7 Yes, 2 ? | |
| | | Psychomotor skills and occupational therapy<br>• Expert opinion | Physical and occupational therapy may be proposed to avoid the over-stimulation or in contrast the under-stimulation from noise, light or touch | 7 Yes, 1 NO, 1? | to my knowlegde evidence is almost unexistant |
| | | Auditory integration (i.e. Tomatis method) | not recommended (grade B) | 7 Yes, 2 ? | |
| | | Music therapy | Insufficient evidence, no recommendation provided | 8 Yes, 1 ? | |
| | | Massage | Insufficient evidence, no recommendation provided | 7 Yes, 1 NA, 1 ? | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | | Sentive integration | Insufficient evidence, no recommendation provided | 7 Yes, 1 NA, 1 ? | |
| Pharmacological intervention | | | | | |
| **No evidence found** | | | | 5 Yes, 2 NA, 2? | |
| Biomedical interventions | | | | | |
| Complementary interventions<br>• Qigong massage training vs. Waitlist<br>Sensory interventions<br>• Auditory integration training vs. attention-placebo | Insufficient evidence, no recommendation provided. However, research recommendation provided for Sensory Integration Therapy. | | | 5 Yes, 1 NA, 3 ? | |
| **5. Intervention domain : *Motor difficulties*** | | | | | |
| Psychosocial interventions | | | | | |
| Animal-based interventions<br>• Horseback riding vs. waitlist control | Insufficient evidence, no recommendation provided | Animal-based interventions | Insufficient evidence, no recommendation provided | 7 Yes, 1 NA, 1 ? | |
| Behavioural interventions<br>• EIBI (EDSM) vs. TAU | Insufficient evidence, no recommendation provided | | | 7 Yes, 2 ? | |
| Educational interventions<br>• LEAP training vs. manual only control | Insufficient evidence, no recommendation provided. However, promising results so research recommendation provided. | | | 7 Yes,1, NA 1 ? | |
| Parent training<br>• Parent training vs. TAU<br>• Parent and day care staff training vs. standard day care | Insufficient evidence, no recommendation provided | | | 8 Yes, 1 ? | parent involvement in motor difficulties should be encouraged and coordinated with professional intervention |
| Social-Communication interventions<br>• Caregiver-mediated social communication intervention vs. TAU | Insufficient evidence, no recommendation provided | | | 7 Yes, 2 ? | |
| | | Physical or occupational therapy<br>• Expert opinion | Recommend physical or occupational therapy in case of praxis, postural, tonic | 6 Yes, 3 ? | SPECIFICATION?-especially in case of comorbid DCD-Appropriate assessment of impairments is mandatory |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | | | or gnostic disorders interfering with daily live (dressing, feeding, leisures) or with school education (writing, reading) | | |
| Pharmacological interventions | | | | | |
| No evidence found | | | | 5 yes, 3 NA, 1 ? | |
| Biomedical interventions | | | | | |
| Hormone interventions<br>• Secretin vs. placebo | Insufficient evidence, no recommendation provided. | | | 5 yes, 3 NA, 1 ? | POSSIBLY HARMFULL: NOT RECOMMENDED |
| Nutritional interventions<br>• Omega-3 fatty acids vs. healthy diet control<br>• Gluten-free and casein free diet vs. TAU | | | | | |
| **6. Intervention domain : *Coexisting mental health problems*** | | | | | |
| Psychosocial interventions | | | | | |
| Cognitive-behavioural interventions<br>• CBT vs. TAU | Consider the following for children and young people with autism and anxiety who have the verbal and cognitive ability to engage in CBT:<br>• group CBT adjusted to the needs of children and young people with autism<br>• individual CBT for children and young people who find group-based activities difficult. | | | 7 Yes, 1 NA, 1 ? | Nécessité d'une bonne analyse de la situation individuelle, familiale et environnementale pour décider de la thérapie la plus adaptée en cas de troubles mentaux associés) |
| | Consider adapting the method of delivery of CBT for children and young people with autism and anxiety to include:<br>• emotion recognition training<br>• greater use of written and visual information and structured worksheets | | | 7 Yes, 2 ? | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | • a more cognitively concrete and structured approach<br>• simplified cognitive activities, for example, multiple-choice worksheets<br>• involving a parent or carer to support the implementation of the intervention, for example, involving them in therapy sessions<br>• maintaining attention by offering regular breaks<br>• incorporating the child or young person's special interests into therapy if possible | | | | |
| Pharmacological interventions | | | | | |
| Pharmacological interventions<br>• Atomoxetine vs. placebo | Insufficient evidence, no recommendation provided. | | | 3 NO, (!) 3 NA, 3 ? | Offer psychosocial and pharmacological interventions for the management of coexisting mental health or medical problems in children and young people with autism in line with NICE guidance for children and young people, including: Antisocial behaviour and conduct disorders in children and young people (NICE clinical guideline 158) Attention deficit hyperactivity disorder (ADHD) (NICE clinical guideline 72) Constipation in children and young people (NICE clinical guideline 99) Depression in children and young people (NICE clinical guideline 28) Epilepsy (NICE clinical guideline 137) Obsessive-compulsive disorder (OCD) and body |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | | | | | dysmorphic disorder (BDD) (NICE clinical guideline 31) Post-traumatic for ASD + ADHD, there is some RCT evidence that atomoxetine has positive effect on comorbid ADHD (Arnold et al. 2006) |
| Biomedical interventions | | | | | |
| Nutritional interventions<br>• Omega-3 fatty acids vs. healthy diet control<br>• Gluten-free and casein free diet vs. TAU<br>• Omega-3 fatty acids vs. Placebo<br>Medical procedure interventions<br>• Long-term chelation (7 rounds of DMSA) vs. Short-term chelation (1 round of DMSA and six rounds of placebo) | Insufficient evidence, no recommendation provided. | | | 5 yes, 3 NA, 1 ? | |
| **7. Intervention domain : *Common medical and functional problems*** | | | | | |
| Psychosocial and pharmacological interventions | | | | | |
| Psychosocial and pharmacological interventions:<br>• CBT vs. placebo<br>• Melatonin vs. placebo<br>• Melatonin vs. placebo<br>• COMB vs. placebo<br>• COMB vs. CBT<br>• COMB vs. Melatonin<br>• Atomoxetine vs. placebo | • For **sleep problems** offer an assessment that identifies:<br>• what the sleep problem is (for example, delay in falling asleep, frequent waking, unusual behaviours, breathing problems or sleepiness during the day)<br>• day and night sleep patterns, and any change to those patterns<br>• whether bedtime is regular<br>• what the sleep environment is like, for example:<br>o the level of background noise<br>o use of a blackout blind | | | 6 Yes, 2 NA, 1 ? | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | o a television or computer in the bedroom<br>o whether the child shares the room with someone<br>• presence of comorbidities especially those that feature hyperactivity or other behavioural problems<br>• levels of activity and exercise during the day<br>• possible physical illness or discomfort (for example, reflux, ear or toothache, constipation or eczema)<br>• effects of any medication<br>• any other individual factors thought to enhance or disturb sleep, such as emotional relationships or problems at school<br>• the impact of sleep and behavioural problems on parents or carers and other family members.<br>If the child or young person with autism snores loudly, chokes or appears to stop breathing while sleeping, refer to a specialist to check for obstructive sleep apnoea. | | | | |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | Develop a sleep plan (this will often be a specific sleep behavioural intervention) with the parents or carers to help address the identified sleep problems and to establish a regular night-time sleep pattern. Ask the parents or carers to record the child or young person's sleep and wakefulness throughout the day and night over a 2-week period. Use this information to modify the sleep plan if necessary and review the plan regularly until a regular sleep pattern is established.<br>Do not use a pharmacological intervention to aid sleep unless:<br>• sleep problems persist despite following the sleep plan<br>• sleep problems are having a negative impact on the child or young person and their family or carers. | | | | |
| | If a pharmacological intervention is used to aid sleep it should:<br>• only be used following consultation with a specialist paediatrician or psychiatrist with expertise in the management of autism or paediatric sleep medicine<br>• be used in conjunction with non-pharmacological interventions | | | 3 Yes , 6 ? | a specialist with expertise in the management of autism or paediatric sleep medicine |

| STATEMENTS: ASSOCIATED FEATURES OF AUTISM AND COEXISTING CONDITIONS | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | **NICE Recommendation** | **HAS guideline** | **HAS Recommendation** | **GDG Yes ; No ; Na/? ; Not specialised** | **Comments** |
| | • be regularly reviewed to evaluate the ongoing need for a pharmacological intervention and to ensure that the benefits continue to outweigh the side effects and risks. | | | | |
| | If the sleep problems continue to impact on the child or young person or their parents or carers, consider:<br>• referral to a paediatric sleep specialist, and<br>• short breaks and other respite care for one night or more. Short breaks may need to be repeated regularly to ensure that parents or carers are adequately supported. Agree the frequency of breaks with them and record this in the care plan. | | | 5 Yes, 4 ?<br>3 Yes , 6 ?<br>4 Yes, 5 ? | a specialist with expertise in the management of autism or paediatric sleep medicine |
| | | Behavioral interventions on **feeding disorders** | Insufficient evidence, no recommendation provided | 5 Yes, 4 ? | Is, nonetheless, often a serious problem and requires attention. |
| Biomedical interventions | | | | | |
| Nutritional interventions:<br>• Multivitamin/mineral supplement vs. placebo<br>• Omega-3 fatty acids vs. healthy diet control<br>• Secretin vs. placebo<br>• Immunoglobulin vs. placebo | Do not use omega-3 fatty acids to manage sleep problems in children and young people with autism. | | | 6 Yes, 1 NA, 2 ? | |
| **8. Intervention domain : *Sexuality*** | | | | | |
| Psychosocial interventions | | | | | |
| | | No evidence | Expert consensus: Propose adapted sexual education | 7 Yes, 1 NA, 1 ? | |

*Legend (column Summary of GDG scores): **y**=yes / **n**=no / **?** =don't know- don't understand / **na**=no answer / **Not specialised** = stated that not specialized in medications and in biomedical intervention*

## 5.5. Interventions aimed at improving the impact on the family (GDG 3 on 31-3-2014)

**Table 21 – Evidence and discussion on domain 5: interventions aimed at improving the impact on the family**

| STATEMENTS: IMPROVING THE IMPACT ON FAMILY | | | | | |
|---|---|---|---|---|---|
| **NICE guideline** | NICE Recommendation | HAS guideline | HAS Recommendation | | |
| **Psychosocial interventions** | | | | | |
| Behavioural interventions<br>· EBI | Insufficient evidence, no recommendation provided | | | 3 Yes, 1 NO, 1 NA, 3? | Testimonials from our experience with families strongly support the use of EBI4)Of course, the impact on family was not fully investigated… but "no recommendation" is a "hard" conclusion!!! |
| Cognitive-behavioural intervention<br>· CBT | Insufficient evidence, no recommendation provided | | | | |
| Parent training<br>• PEBM Parent education and behaviour management/ PEC parent education and counselling;<br>• training of parents by speech and language therapists;<br>• home TEACCH;<br>• hospital-based seminar, on-site consultations to day care centres, psycho-educational and supportive training | Insufficient evidence, no recommendation provided | | | 4 Yes, 1 NA, 3 ? | See comment above-Attention à ce que les parents ne deviennent pas des éducateurs superspécialisés de leur enfant et mette à mal l'ensemble du système familial par un travail top intensif avec l'enfant. |
| | | Observational evaluation, qualitative research and expert opinion | It is recommended to facilitate support of parents and to propose different support modalities:<br>• Information on autism and on interventions;<br>• Support to understand particular challenges experienced by their child with autism;<br>• Psychological support;<br>• Exchange of experience among parents;<br>• Contacts with parents associations or with other persons with autism; | 6 Yes, 2 ? | |

| | | | |
|---|---|---|---|
| | | Information on and support to get access to professional help; in particular guidance when the child/adolescent needs to be (re-)oriented | |
| | Expert opinion | It is recommended that special attention be paid to signs of suffering and seeking for support expressed by siblings and to propose different modalities:<br>• individual psychological support;<br>• thematic groups 'parents-children-sibling';<br>• discussion groups;<br>• organized activities with the sibling, etc.<br>These modalities cannot be imposed. | 6 Yes, 2 ? |

*Legend (column Summary of GDG scores): **y**=yes / **n**=no / **?** =don't know- don't understand / **na**=no answer / **Not specialised** = stated that not specialized in medications and in biomedical intervention*

## 5.6. Adverse events associated with interventions (GDG 2 on 24-2-2014)

**Table 22 – Evidence and discussion on domain 6: adverse events**

| STATEMENTS: ADVERSE EVENTS | | | | | |
|---|---|---|---|---|---|
| **NICE RECOMMENDATION** | **HAS GUIDELINE** | **HAS RECOMMENDATION** | **GDG yes; no; na/?; not specialised** | | **COMMENTS** |
| | Expert opinion: when prescribing psychotropic drugs benefits and risks should be balanced | recommend | Yes<br>No<br>NA<br>?<br>Not speciacialized | **9**<br><br><br>**1** | of course |
| | Expert opinion: Parents should receive written informationon the drugs that are prescribed | recommend | Yes<br>No<br>NA<br>?<br>Not speciacialized | **9**<br>**1** | 1) as well as oral<br>2) also on adverse effects<br>3)This is not usual in Belgium, while giving proper explanation and help in getting extra info is usual (or should be, to my opinion).<br>4) Parents and youngsters should consent after being informed extensively on the effects and potential sideeffects of drugs that are prescribed |

# 6. RESULTS OF THE DELPHI SURVEYS BY DOMAIN

## 6.1. Organisation and delivery of care

### *6.1.1. Round 1: level of agreement and comments*

Number of participants= 11

**Table 23 – Organisation and delivery of care: Delphi round 1**

| AUTISM Organisation and delivery of care: KCE recommendations | | | | |
|---|---|---|---|---|
| | | **Yes** | **No** | **Comments on Organisation and delivery of care** |
| **Organisation and delivery of care** | | | | |
| **1** | All staff working with children and young people with autism should have an understanding of autism. | 100% | 0% | ********** |
| **2** | In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit the negative impact of the environment | 100% | 0% | ********** |
| **3** | Children and young people with autism should have access to a keyworker approach in order to manage and coordinate treatment, care and support, including the management of transitions, for the child or young person with autism and their family and carers. | 100% | 0% | ********** |
| **4** | Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities. | 100% | 0% | ********** |
| **5** | Children and young people with autism and their family and carers, should have easy access to short breaks, especially at periods of severe stress for the child and/or family. | 100% | 0% | ********** |
| **6** | Children and young people with autism, and their family and carers, should be provided with post-diagnosis information about services available and support, for example a family support worker. | 100% | 0% | ********** |

| | | | | |
|---|---|---|---|---|
| **7** | Treatment and care of children and young people with autism should involve shared decision making and a collaborative approach that takes into account service user preferences. | 100% | 0% | ********** |
| **8** | All children and young people with autism should have access to healthcare and social care services, including mental health services. Services should be adapted to the level of care specialisation the child needs. Services should be within a reasonable distance from their homes. Access should take the level of functional impairement into account but should not be restricted based on a child's intellectual ability, autism diagnosis, or any other eligibility criteria. | 92% | 8% | *Besides healthcare and social care, don't forget the educational services, because in Belgium the major status is first "pupils and students" |
| **Stakes and principles of action** | | | | |
| **9** | A coherent multidisciplinary approach is needed. | 92% | 8% | *What is ment by multidisciplinary approach: it is better to specify. |
| **10** | Define a framework and quality criteria for multi (trans) disciplinary approach in the same or in different institutions. | 92% | 8% | *Though I favour broad rules for multidisciplinary approach, including criteria to measure quality of services, I am not in favour of strict protocols ("recipe books") that have to be implemented in all settings and to all patients. At least define a set of different protocol options. Consequently, I would like to see this RC more nuanced. |
| **11** | A therapeutic team should establish a framework for an individualized work plan and should identify a coordinator. | 92% | 8% | *What about the "educational team"? I propose : "A therapeutic and educational team should.." |
| **12** | A framework and quality criteria should be formalised within an institution, in conventions with other professionals, in networks. | 85% | 15% | *similar as RC 27: broad rules and quality criteria, but no strict protocols, or at least a choice of protocols.<br>*What is the meaning of rules ? Please give examples ! Ethical rules ? The model used ? |
| **13** | The framework and quality criteria should be known by all professionals. | 92% | 8% | *See above |
| **14** | The personalised educational plan should reflect the framework and quality criteria. | 92% | 8% | *See above |
| **Tools for improving coherent intervention** | | | | |
| **15** | Develop a personalised program based on evaluation with appropriate tools and on observation in daily life, and in agreement with the patient, the parents and all professionals involved. | 92% | 8% | *"in agreement with the person" (or the child and adolescent) |

| | | | | |
|---|---|---|---|---|
| **16** | Assign the task of coordinator to one of the professionals (not necessarily an MD) in order to guarantee the coherence and continuity of care. | 92% | 8% | *In close collaboration with the parents |
| **17** | A person who had a comprehensive training (including all the important aspects of ASS) will be responsible for overseeing and/or delegating the coordination task. | 100% | 0% | ********** |
| **18** | A file (case record, dossier) is the source document for communication between professionals. | 100% | 0% | ********** |
| **19** | The file should contain all relevant information on the patient: personalised project, evaluations, treatment plan, specific interventions. | 85% | 15% | * "person" instead of "patient"<br>- treatment and educational plan<br>*Who will look to the file that it will stay op to date??? |
| **20** | Sharing the file necessitates parental consent, in line with the rules of duty of professional confidentiality. | 100% | 0% | ********** |
| **21** | In professional communication, it is recommended to use the DSM V classification. | 77% | 23% | *should be DSM-5<br>*je suis plutôt d'accord, mais j'ai écrit "I do not agree" pour faire un commentaires. même si le DSM V est publié depuis 2013, il n'y a pas encore de traduction en français et pas d'outil diagnostique basé sur le DSM V...<br>*No advice no specialist<br>*or the ICD !<br>But the DSM 5 has major improvements ... |
| **22** | A go-between notebook or electronic tool is recommended to support communication between the professionals and the parents and child. | 92% | 8% | *This tool has not to be systematic |
| **23** | Upon transfer between institutions (medical/social) a contact person (referent) should be kept until integration for the child and his family is ensured. | 100% | 0% | ********** |
| **24** | Networking, collaboration and regular meetings should be organized between professionals. | 92% | 8% | *with the parents and the person ! |
| **25** | The Reference centres for Autism have a specific role in supporting the networking. | 92% | 8% | * While I agree, I strongly doubt whether this is feasible, due to limited capacity of the RCA.<br><br>* A significant number of Ambulatory Rehabilitation Centers (CAR's) can provide this role as well. |
| **26** | Institutions, especially hospitals, should offer protocols to facilitate first contacts. | 92% | 8% | *rather vague, moreover, why especially hospitals? |

| | | | | |
|---|---|---|---|---|
| **27** | A medical examination by a medical doctor familiar with ASD should be offered at the start of the screening and whenever needed. | 85% | 15% | *At least one, and if necessary later medical examinations are surely recommendable. THe annual rhythm does not make much sense for a substantial number of patients, and the free choice by parents may lower the quality of the medical examination, as lots of specialists and GP's are not familiar with ASD.<br>*I think that an examination every year is not necessary for all children. |
| **Sensitive transition periods** | | | | |
| **28** | Diagnostic and therapeutic teams should collaborate closely. Professionals who intervene only occasionally should consult the team. | 92% | 8% | *Don't forget "educational teams" |
| **29** | Participation of representatives of therapeutic teams should be offered to parents early on during the information sessions on the diagnosis. | 85% | 15% | *parents should be free to have an initial information session without onlookers (privacy)<br>*and educational teams… |
| **30** | Transition periods e.g. transfer from one type of care/education to another or from childhood to adulthood require particular attention and should be prepared. Continuity of care should be assured. | 100% | 0% | ********** |
| **31** | Crisis situations require specific evaluation and intervention. Necessary information should be communicated among professionals, also in case hospitalization is inevitable. Specific education of professionals about crisis situations is necessary. | 100% | 0% | ********** |
| **Education and support for professionals** | | | | |
| **32** | Continuous education (at least every 2 to 3 years) is needed for all professionals. | 92% | 8% | *at least every 2 years, 3 years is a long period |
| **33** | Therapeutic teams should be accompanied by an external expert (representing a reference centre for autism) for debriefings once per year. | 92% | 8% | *good in theory, but not feasible for the moment, skip (representing a reference centre for autism) |
| **34** | Professionals should not work in isolation but share experiences with peers or be supervised. | 100% | 0% | ********** |
| **35** | New professionals should be coached. | 100% | 0% | ********** |
| **36** | Awareness and support should be offered to professionals to prevent burn-out. | 100% | 0% | ********** |

## 6.2. Core features of autism

### *6.2.1. Round 1: level of agreement and comments*

Number of participants= 11

**Table 24 – Core features of autism: Deplhi round 1**

| AUTISM core features: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments on core features |
| | | Yes | No | |
| **Psychosocial interventions** | | | | |
| **Overall autistic behaviour** | | | | |
| **1** | Regarding psychosocial interventions for overall autistic behaviour, there is overall insufficient evidence that any type of intervention (behavioural, educational, parent training, social communication intervention) has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 69% | 31% | *we should first define what overall atistic behaviour is, because in what follows the core features (social communication and stereotyped behaviour) will come back<br>*I do propose to take consideration of the HAS conclusions<br>*je pense qu'il y a quand même des approches psycho-éducatives qui - de façon générale- apportent des bénéfices aux personnes avec autisme<br>*Literature and testimonials on internet point to some behavioural and educational methods (ABA, PECS,...)having effects, sometimes important with some, albeit not all, children with autism. Parents are aware of this information and expect KCE study to reflect this and take a position. Putting in the same category all interventions that do not meet the EBM standards of scientific proof does not correctly reflect the situation. Some interventions have some effect, others none at all. We should introduce an intermediate category between "recommended" and "not recommended". NCA study (USA) and HAS study (France) use this intermediary level (emerging or level 2 evidence); Given that KCE recommendations will set the guidelines for years to come in Belgium, this npoint is very important |

| AUTISM core features: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments on core features |
| | | Yes | No | |
| **2** | There is no evidence on the effect of individual psychoanalysis, therefore no recommendation can be provided. | 92% | 8% | *psychoanalysis starts from a model of autism etiology which is in contradiction with recent progress in neurobiology and "imagerie médicale".<br><br>*The interventions that it proposes reject evaluation and reporting of results in the name of uniqueness of the therapeutic relation. This is in contradiction with the very concept of evidence based recommendations for interventions (EBM). individual psychoanaysis should therefore be "not recommended" as refusing to provide proof of effectiveness. |
| **3** | There is no evidence on the effect of treatment in psychoanalytically oriented institutions, therefore no recommendation can be provided. | 92% | 8% | *See comments above. Institutions should at least provide some record of the results of their interventions on their patients |
| **Impaired reciprocal social communication and interaction** | | | | |
| **4** | Regarding psychosocial interventions for impaired reciprocal social communication and interaction, the following interventions aimed at improving social communication: EBI/EIBI and joint attention training, LEGO therapy and social skills groups are recommended. | 62% | 38% | * No evidence for LEGO<br>effect of social skills groups limited to some subgroups of ASD<br>*I don't see why we should mention LEGO therapy separately, the evidence is based on 1 study only, neither NICE, nor HAS mention this in their recommendations<br>*How to consider that those programs have an impact on this whole domain ? ... mainly with the aspect of DSM5 is new ... have those programs been evaluated in this way ?<br>*Some kinds of therapy are called bij name, others are not. *I think this recommendation is too specific in mentioning eg LEGO therapy |
| **5** | Regarding psychosocial interventions for *impaired reciprocal social communication and interaction,* there is insufficient evidence that animal based, arts based, behavioural, cognitive or educational intervention, parent training or PECS has an | 62% | 38% | *this is in contradiction with the previous, because EBI/EIBI are behavioural interventions; moreover, we should make a clear distinction between parent training and parent-mediated interventions (the latter are recommended in NICE)<br>*Same consideration of RC4. Some program as PECS focused |

| AUTISM core features: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments on core features |
| | | Yes | No | |
| | effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | | | on communiaction and not on recirpocal socila communication.<br><br>*il me semble peu judicieux de recommander la lego therapy (RC4) alors que les interventions cognitives, comportementales et éducatives, ainsi que la formation de parents et le PECS ne le sont pas<br>*I agree for : animal based and arts based...<br>*There is insufficient proof about ABA and PECS in terms of EBM standards. However some evidence is available |
| **Restricted interests and rigid and repetitive behaviours** | | | | |
| **6** | Regarding psychosocial interventions for *restricted interests and rigid and repetitive behaviours,* there is insufficient evidence that behavioural, cognitive or social-communication intervention or parent training has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 85% | 15% | *The "insufficient evidence" does not take into account le evidence based upon the experimental single case designs |
| **Pharmacological interventions** | | | | |
| **Overall autistic behaviour** | | | | |
| **7** | Pharmacological interventions involving antipsychotics, anticonvulsants and antidepressants are not recommended to target *overall autistic behaviour*. | 75% | 25% | *I am not a specialist so I have no advice<br>*I am not specialized in medications<br>*I agree that it is not recommended for the autistic behaviour, but it can be recommended for behavioural problems which are comorbid. |
| **8** | Regarding pharmacological intervention for *overall autistic behaviour* there is insufficient evidence on the effect of SNRI's and therefore no recommendation can be provided. | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |
| **Impaired reciprocal social communication and interaction** | | | | |
| **9** | Regarding pharmacological intervention for *impaired reciprocal social communication and interaction* there is insufficient | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |

| AUTISM core features: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments on core features |
| | | Yes | No | |
| | evidence on the effect of antioxydants and therefore no recommendation can be provided. | | | |
| **Restricted interests and rigid and repetitive behaviours** | | | | |
| **10** | A) Regarding pharmacological interventions involving antidepressants (especially SSRI's) no recommendation can be provided to target *restricted interests and rigid and repetitive behaviours* because of insufficient evidence.<br>B) Pharmacological interventions involving antioxidants are not recommended to target restricted interests and rigid and repetitive behaviours. | 75% | 25% | antioxidants not recommended,<br>but some evidence that antidepressants may be effective; so I would split up antioxidants (not recommended) and SSRRI's (no recommendation)<br>*Fluoxetine heeft wel een lichte verbetering van RRRB (d'hollander 2005)<br><br>verschil maken tussen antidepressiva en antioxidantia?<br>*I am not specialized in medications |
| **Biomedical interventions** | | | | |
| **Overall autistic behaviour** | | | | |
| **11** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target *overall autistic behaviour.* | 91% | 9% | *No advice not a specialist<br><br>*I am not specialized in medications |
| **12** | Biomedical interventions involving other drugs such as antibiotics, antifungals, dextrometorphan, famotidine, amantadine, benzodiazepines and antihistamines are not recommended to target *overall autistic behaviour.* | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |
| **13** | Regarding biomedical intervention for *overall autistic behaviour,* there is insufficient evidence on the effect of complementary interventions (such as acupressure,acupuncture,electro-acupuncture and Qigong massage), nutritional interventions (with multivitamins and minerals, L- carnosine or L-carnitine, omega-3fatty acids) and sensory interventions (neurofeedback and auditory integration training). Therefore no recommendation can be provided for these interventions. | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |

| AUTISM core features: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments on core features |
| | | Yes | No | |
| **Impaired reciprocal social communication and interaction** | | | | |
| **14** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target *impaired reciprocal social communication and interaction.* | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |
| **15** | Regarding biomedical intervention for *impaired reciprocal social communication and interaction,* there is insufficient evidence on the effect of complementary interventions (electro-acupuncture), nutritional interventions (multivitamins and minerals, L- carnosine or L-carnitine, omega-3 fatty acids) and sensory interventions (neurofeedback). Therefore no recommendation can be provided for these interventions. | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |
| **Restricted interests and rigid and repetitive behaviours** | | | | |
| **16** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target *restricted interests and rigid and repetitive behaviours.* | 91% | 9% | *No advice not a specialist<br>*I am not specialized in medications |
| **17** | Regarding biomedical intervention for *restricted interests and rigid and repetitive behaviours,* there is insufficient evidence on the effect of motor intervention (Kata excercise training) nutritional interventions (L- carnosine or L-carnitine) and sensory interventions (neurofeedback). Therefore no recommendation can be provided for these interventions | 92% | 8% | *I am not specialized in medications |

### 6.2.2. Round 2: level of agreement

Number of participants= 12

**Table 25 – Core features of autism: Delphi round 2**

| AUTISM core features: KCE recommendations | | Level of agreement | |
|---|---|---|---|
| | | Yes | No |
| **Psychosocial interventions** | | | |
| **Overall autistic behaviour** | | | |
| **1** | Regarding psychosocial interventions for overall autistic behaviour, there is overall insufficient evidence that any type of intervention (behavioural, educational, parent training, social communication intervention) has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 36% | 64% |
| **Impaired reciprocal social communication and interaction** | | | |
| **4** | Regarding psychosocial interventions for impaired reciprocal social communication and interaction, the following interventions aimed at improving social communication: EBI/EIBI and joint attention training, LEGO therapy and social skills groups are recommended. | 45% | 55% |
| **5** | Regarding psychosocial interventions for impaired reciprocal social communication and interaction, there is insufficient evidence that animal based, arts based, behavioural, cognitive or educational intervention, parent training or PECS has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 60% | 40% |
| **Restricted interests and rigid and repetitive behaviours** | | | |
| **6** | Regarding psychosocial interventions for restricted interests and rigid and repetitive behaviours, there is insufficient evidence that behavioural, cognitive or social-communication intervention or parent training has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 70% | 30% |
| **Pharmacological interventions** | | | |
| **Overall autistic behaviour** | | | |

| AUTISM core features: KCE recommendations | | Level of agreement | |
|---|---|---|---|
| | | Yes | No |
| **7** | Regarding psychosocial interventions for restricted interests and rigid and repetitive behaviours, there is insufficient evidence that behavioural, cognitive or social-communication intervention or parent training has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 91% | 9% |
| **Restricted interests and rigid and repetitive behaviours** | | | |
| **10** | A) Regarding pharmacological interventions to target restricted interests and rigid and repetitive behaviours, there is insufficient evidence on the effect of antidepressants (especially SSRI's) and therefore no recommendation can be provided.<br>B) Pharmacological interventions involving antioxidants are not recommended to target restricted interests and rigid and repetitive behaviours. | 100% | 0% |
| **Stakes and principles of action** | | | |
| **29** | A framework and quality criteria should be formalised within an institution, in conventions with other professionals, in networks. | 100% | 0% |
| **Tools for improving coherent intervention** | | | |
| **36** | The file should contain all relevant information on the person with autism: personalised project, evaluations, treatment and educational plan, specific interventions. | 100% | 0% |
| **38** | In professional communication, it is recommended to use the DSM-5 classification. | 100% | 0% |
| **44** | A medical examination by a medical doctor familiar with autism and chosen by the parents should be offered at the start of the screening and whenever needed. | 100% | 0% |
| **Sensitive transition periods** | | | |
| **46** | Participation of representatives of therapeutic teams should be offered to parents early on during the information sessions on the diagnosis. | 100% | 0% |

### *6.2.3. Round 3: level of agreement*

Number of participants= 11

**Table 26 – Core features of autism: Delphi round 3**

| AUTISM core features: KCE recommendations | | Level of agreement | |
|---|---|---|---|
| | | Yes | No |
| **Psychosocial interventions** | | | |
| **Overall autistic behaviour** | | | |
| **1** | 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. | 92% | 8% |
| **Impaired reciprocal social communication and interaction** | | | |
| **4** | **DELETED** | | |
| **5** | **DELETED** | | |
| **Restricted interests and rigid and repetitive behaviours** | | | |
| **6** | Regarding the core feature of *restricted interests and rigid and repetitive behaviours,* there is insufficient evidence that behavioural, cognitive or social-communication interventions or parent training have an effect. Therefore no recommendation can be provided regarding psychosocial interventions for this core feature. | 80% | 20% |

## 6.3. Behaviour that challenges

### *6.3.1. Round 1: level of agreement and comments*

Number of participants= 12

**Table 27 – Behaviour that challenges: Delphi round 1**

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| **Anticipating and preventing behaviour that challenges** | | | | |
| **1.** | Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:<br>• impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes<br>• coexisting physical disorders, such as pain or gastrointestinal disorders<br>• coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD<br>• the physical environment, such as lighting and noise levels<br>• the social environment, including home, school and leisure activities<br>• changes to routines or personal circumstances<br>• developmental change, including puberty<br>• exploitation or abuse by others<br>• inadvertent reinforcement of behaviour that challenges | 100% | 0% | |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| | • the absence of predictability and structure. | | | |
| **2.** | Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:<br>• treatment, for example, for coexisting physical, mental health and behavioural problems<br>• support, for example, for families or carers<br>• necessary adjustments, for example, by increasing structure and minimising unpredictability. | 100% | 0% | |
| **Assessment and initial intervention for behaviour that challenges** | | | | |
| **3.** | If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could provoke the behaviour. | 100% | 0% | |
| **4.** | Offer the following to address factors that may trigger or maintain behaviour that challenges:<br>• treatment for physical disorders, or coexisting mental health and behavioural problems<br>• interventions aimed at changing the environment, such as:<br>• providing advice to families and carers<br>• making adjustments or adaptations to the physical surroundings | 100% | 0% | |
| **5.** | If behaviour remains challenging despite attempts to address the underlying possible causes, consult | 100% | 0% | |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| | senior colleagues and undertake a multidisciplinary review. | | | |
| **6.** | At the multidisciplinary review, take into account the following when choosing an intervention for behaviour that challenges:<br>• the nature, severity and impact of the behaviour<br>• the child or young person's physical and communication needs and capabilities<br>• the environment<br>• the support and training that families, carers or staff may need to implement the intervention effectively<br>• the preferences of the child or young person and the family or carers<br>• the child or young person's experience of, and response to, previous interventions. | 100% | 0% | |
| **Functional assessment** | | | | |
| **7** | In the case of challenging behaviour a functional assessment should first be performed. | 100% | 0% | |
| **8** | The functional assessment should include a medical examination in order to exclude physical causes for pain. | 100% | 0% | |
| **9** | The functional assessment should identify<br>• triggers for the behaviour,<br>• patterns of behaviour,<br>• the needs that the child or young person is attempting to meet by performing the behaviour,<br>• the consequences of the behaviour. | 92% | 8% | 1) A functionnal assessment should identify also the setting events and the FUNCTION of the behavior (not only the consequence). It should also identify the problems in the "system" around the child (family, services, organization, ...). |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| **Psychosocial intervention** | | | | |
| **10** | 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. | 78% | 8% | 1) there is no evidence this should work 2) I don't know what is a "psychosocial" intervention in this sector. |
| **11** | There is insufficient evidence to recommend any specific type of psychosocial intervention. | 89% | 11% | 1) same comment of RC10 |
| **12** | Psychosocial interventions for behaviour that challenges should include clearly identified target behaviour. | 80% | 20% | 1) same comment of RC10 |
| **13** | Psychosocial interventions for behaviour that challenges should include a focus on outcomes that are linked to quality of life. | 91% | 9% | 1) I do agree with the fact that any intervention should include a focus on outcomes that are linked to QoL |
| **14** | Psychosocial interventions for behaviour that challenges should include assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour. | 91% | 9% | 1) If we answer "I agree" we say that a psycho-social intervention is a behavioral intervention. I would agree with that but it is sont the way of the succession of RC |
| **15** | Psychosocial interventions for behaviour that challenges should include a clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person. | 91% | 9% | 1) same comment of RC10 |
| **16** | Psychosocial interventions for behaviour that challenges should include a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time). | 90% | 10% | 1) same comment of RC10 and RC14 |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| **17** | Psychosocial interventions for behaviour that challenges should include a systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met. | 89% | 11% | 1) same comment of RC10 and RC14 |
| **18** | Psychosocial interventions for behaviour that challenges should be applied consistently in all areas of the child or young person's environment (for example, at home and at school). | 82% | 18% | 1) Depends on weather or not al the environments experience the behaviour as 'challenging'?<br>2) same comment of RC10 and RC14 |
| **19** | Psychosocial interventions for behaviour that challenges should include agreement among parents, carers and professionals in all settings about how to implement the intervention. | 82% | 18% | 1) Agreement of the child if old enough? (cfr Decreet Rechtspositie Minderjarige binnen Integrale Jeugdhulp in Vlaanderen)...ook duidelijkheid wat moet gebeuren als een van beide ouders niet akkoord gaat maar er toch een duidelijk nood is?<br>2) same comment of RC10 and RC14 |
| **Crisis intervention** | | | | |
| **20** | Crisis intervention should aim at providing protection, not punishment**.** | 100% | 0% | |
| **21** | The use of isolation chambers should be restricted to exceptional cases where all other approaches have failed and the person and the environment need protection. | 100% | 0% | |
| **22** | The use of isolation chambers should respect legal regulations and framework. | 100% | 0% | |
| **23** | The use of physical restraint should be restricted to exceptional cases where all other approaches have failed and the person and the environment need protection. | 100% | 0% | |
| **24** | It is recommended not to use packing (wrapping in cold, wet towels). | 100% | 0% | |
| **Pharmacological interventions** | | | | |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| **25** | 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. | 100% | 0% | |
| **26** | Prior to prescribing antipsychotic medication it is recommended to offer a full medical assessment including laboratory and/or functional tests upon indication. | 100% | 0% | |
| **27** | Antipsychotic medication should be prescribed and monitored by a child psychiatrist, a neuropediatrician or an experienced pediatrician or neurologist. | 89% | 11% | 1) we should say a experienced child psychiatrist or neuropediatrician. "experienced" in the field of challenging behavior in the domain of autism. |
| **28** | It is recommended that the prescriber identifies the target behaviour. | 100% | 0% | |
| **29** | It is recommended that the prescriber decides on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact. | 100% | 0% | |
| **30** | It is recommended that the prescriber reviews the effectiveness and any side effects of the medication after 3–4 weeks and regularly thereafter. | 100% | 0% | |
| **31** | It is recommended that the prescriber stops treatment if there is no indication of a clinically important response at 6 weeks. | 100% | 0% | |
| **32** | The prescription of antipsychotic medication should start at a low dose and should be maintained at the minimal effective dose. | 100% | 0% | |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| **33** | It is recommended not to allow caretakers or parents increase the dose 'as needed'**.** | 100% | 0% | |
| **34** | The choice of antipsychotic medication should take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate) and response to previous treatment with an antipsychotic. | 100% | 0% | |
| **35** | When a patient is transferred to primary care clear instructions should be provided regarding all aspects of the prescription but the responsibility is not transferred. | 90% | 10% | 1) La question de la responsabilité est importante et doit être précisée. Si un patient est délégué dans un autre centre de soins primaires, il n'est pas dit qu'il reviendra régulièrement revoir le médecin prescripteur initial. Alors, celui qui prescrit devient responsable de la situation. Le risque est que le patient n'est renvoyé que en cas de crise ou d'urgence chez le spécialiste !!! |
| **36** | The medical expert (child psychiatrist, specialist) should remain in charge of pharmacological treatment and see the patient at least once a year. | 100% | 0% | 1) I'm surprised to read that Haloperidol is in this list. |
| **37** | Pharmacological treatment should be explained to the parents in a comprehensible way, if needed with written information on the therapeutic plan. | 100% | 0% | |
| **38** | 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, risperdone and aripiprazole. | 75% | 25% | |
| **Biomedical interventions** | | | | |
| **39** | It is recommended to inform parents that currently trials involving massage, multivitamin and mineral supplement, electro-acupuncture, hormone treatment (secretin), medical procedures (HBOT and DMSA), nutritional and sensory interventions | 90% | 10% | 1)It would be interessant to separate these informations. Some studies are caried out about multivitamin and mineral supplement, it is sometimes proposed and evaluated in some centers, not as a solution but as a trial. |

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | Comments |
| | | Yes | No | |
| | have not demonstrated efficacy against challenging behaviour in autism. | | | |
| **40** | It is recommended to warn parents against unnecessary spending for alternative treatments that have not shown efficacy. | 100% | 0% | |

### *6.3.2. Round 2: level of agreement*

Number of participants= 13

**Table 28 – Behaviour that challenges: Delphi round 2**

| Intervention and clinical practice recommendations for behaviour that challenge: KCE recommendations | | | |
|---|---|---|---|
| | | Level of agreement Yes | No |
| **Psychosocial intervention** | | | |
| **10** | 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. | 100% | 0% |
| **11** | There is insufficient evidence to recommend any specific type of psychosocial intervention. However, the psychosocial intervention should follow the recommendations outlined below. | 100% | 0% |
| **18** | Psychosocial interventions for behaviour that challenges should be applied consistently in all areas of the child or young person's environment (for example, at home and at school). | 100% | 0% |
| **19** | Psychosocial interventions for behaviour that challenges should include agreement among parents, carers and professionals in all settings about how to implement the intervention. | 100% | 0% |
| **Pharmacological interventions** | | | |
| **38** | 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, risperdone and aripiprazole. | 100% | 0% |

## 6.4. Associated features of autism and coexisiting conditions

### *6.4.1. Round 1: level of agreement and comments*

Number of participants= 8

**Table 29 – Associated features of autism and coexisiting conditions: Delphi round 1**

| Associated conditions: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| **Impairments in adaptive behaviour** | | | | |
| **1.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairement in adaptive behaviour. | 83% | 17% | See for example a recent study By Durand et al. (2012). Positive Family Intervention for severe challenging Behavior I : a multisite randomized clinicla trial. Journal of Positive Behavior Interventions, 15(3), 133-143. |
| **2.** | Pharmacological interventions, including Aripiprazole, are not recommended to treat impairment in adaptive behaviour in children with autism. | 67% | 33% | shouldn't we say 'there is insufficient scientific evidence?' |
| **3.** | Biomedical interventions including complementary interventions (e.g. acupuncture), hormone intervention (e.g. secretin), medical procedures (chelation or HBOT) and nutritional interventions (omega-3 fatty acids, gluten-free or casein-free diet) are not recommended to treat impairment in adaptive behaviour in children with autism. | 100% | 0% | |
| **4.** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve impairments in adaptive behaviour in children with autism | 100% | 0% | |
| **Speech and language problems** | | | | |
| **5.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend augmentative and alternative communication techniques such as PECS, TAU or RPMT for speech and language problems in children with autism. | 67% | 33% | a) - if evidence-based approach means only RCT !<br>- OK for TAU<br>- RPMT ?<br>b) we have a large number of testimonials from parents |

| Associated conditions: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| | | | | using PECS and observing improvement in communication skills. This is not systematic with all children but is the case with most situations |
| **6.** | 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 and should be initiated early on. | 100% | 0% | |
| **7.** | There is insufficient evidence to recommend arts-based interventions to address speech and language problems in children with autism. | 100% | 0% | |
| **8.** | There is insufficient evidence to recommend any type of behavioural or educational interventions to address speech and language problems in children with autism. | 80% | 20% | - if Evidence-based only means RCT ! |
| **9.** | There is insufficient evidence to recommend parent training to address speech and language problems in children with autism. | 67% | 33% | a) - if Evidence-based only means RCT !<br>b) many parents have purchased PECS training and material and use it at home with success. We advise it to our contacts |
| **10.** | Based on expert consensus speech therapy is recommended in autistic children with identified speech and language problems | 100% | 0% | |
| **11.** | The indication for speech therapy should be determined independent of the child' s IQ and should be integrated in a multidisciplinary approach. | 100% | 0% | |
| **12.** | The goals of speech therapy should be clearly defined and the effect be evaluated regularly. | 100% | 0% | |
| **13.** | Pharmacological interventions are not recommended to treat speech and language problems in children with autism. | 100% | 0% | |
| **14.** | Biomedical interventions, including complementary interventions (acupuncture), hormonal therapies (secretin), medical procedures (chelation or HBOT) and nutritional intervention (including omega- | 100% | 0% | |

| Associated conditions: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| | 3 fatty acids, multivitamins or L-carnosine ) are not recommended to treat speech and language problems in children with autism. | | | |
| **15.** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve speech and language problems in children with autism | 100% | 0% | |
| **16.** | It is recommended not to use the 'hands on' techniques of 'facilitated communication' for speech and language problems in children with autism. | 100% | 0% | |
| **17.** | It is recommended not to use auditory integration training for speech and language problems in children with autism. | 100% | 0% | |
| **18.** | It is recommended not to use neurofeedback for speech and language problems in children with autism. | 100% | 0% | |
| **IQ, academic skills and learning** | | | | |
| **19.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention to improve IQ, academic skills and learning in children with autism. | 86% | 14% | if Evidence-based only means RCT ! |
| **20.** | Based on expert consensus, the implementation of an educational intervention such as LEAP , an alternative program for preschoolers and parents, should be considered and studied to improve IQ, academic skills and learning in children with autism. . | 100% | 0% | |
| **21.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend parent training to improve IQ, academic skills and learning in children with autism. However, expert consensus is to encourage parent involvement. | 100% | 0% | |
| **22.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend specific social-communication interventions to improve IQ, academic skills and learning in children with autism. | 83% | 17% | if Evidence-based only means RCT ! |
| **23.** | Pharmacological interventions are not recommended to improve IQ, academic skills and learning in children with autism. | 100% | 0% | |

| Associated conditions: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| **24.** | Biomedical interventions, such as acupuncture, hormonal therapy (secretin), multivitamins and auditory integration training are not recommended to improve IQ, academic skills and learning in children with autism. | 100% | 0% | |
| **25.** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve IQ, academic skills and learning in children with autism. | 100% | 0% | |
| **Sensory sensitivities** | | | | |
| **26.** | There is insufficient evidence to recommend animal-based interventions such as horseback riding to treat sensory sensitivities in children with autsim. | 100% | 0% | |
| **27.** | There is insufficient evidence to recommend educational interventions to treat sensory sensitivities in children with autsim. | 100% | 0% | |
| **28.** | Pharmacological interventions are not recommended to treat sensory sensitivities in children with autism. | 100% | 0% | |
| **29.** | There is insufficient evidence to recommend biomedical interventions such as massage and auditory integration therapy | 100% | 0% | |
| **30.** | Based on expert consensus the use of sensory integration therapy, and various massage techniques should be studied to evaluate the effect on sensory sensitivities in children with autism. | 86% | 14% | what is the meaning of "various massage techniques "? |
| **31** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to treat sensory sensitivities | 100% | 0% | |
| **Motor difficulties** | | | | |
| **32.** | There is insufficient evidence to recommend animal-based interventions such as horseback riding to treat motor difficulties in children with autsim. | 100% | 0% | |
| **33.** | There is insufficient evidence to recommend behavioural interventions to treat motor difficulties in children with autsim. | 86% | 14% | if Evidence-based only means RCT ! |
| **34.** | Based on expert consensus the implementation of an educational intervention such as LEAP, an alternative program for preschoolers | 100% | 0% | |

| Associated conditions: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| | and parents, should be considered and studied to improve motor difficulties in children with autism. | | | |
| **35.** | There is insufficient evidence to recommend parent training to treat motor difficulties in children with autism. | 100% | 0% | |
| **36.** | There is insufficient evidence to recommend social-communication interventions to treat motor difficulties in children with autism. | 100% | 0% | |
| **37.** | Based on expert consensus, physical therapy should be considered in case of comorbid developmental coordination disorder, or other well specified motor problems that interfere with daily life, but only after clinical assessment and with regular re-assessments. | 86% | 14% | I do agree but want to add following: the physical therapy has to be task-oriented with focus on the transfer in daily life acitivities. |
| **38.** | Pharmacological interventions are not recommended to treat motor difficulties in children with autism. | 100% | 0% | |
| **39.** | There is insufficient evidence for the use of biomedical interventions, such as hormonal therapy (secretin), nutritional interventions (omega-3 fatty acids, gluten-free or casein-free diet) to treat motor difficulties in children with autism. | 100% | 0% | |
| **40.** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to treat motor difficulties | 100% | 0% | |
| **Coexisting mental health problems** | | | | |
| **41.** | It is recommended to consider a cognitive-behavioural intervention to treat anxiety in children with autism who have the required verbal and cognitive ability to engage in CBT. | 100% | 0% | |
| **42.** | CBT should only be initiated after a thorough assessment of the child and with regular re-assessment performed. | 100% | 0% | |
| **43.** | It is recommended to adapt CBT to individual needs and the child's environment and to involve the parents in the treatment plan. | 100% | 0% | |
| **44.** | It is recommended to consult the appropriate NICE recommendations for specific coexisiting mental health problems. | 100% | 0% | |

| Associated conditions: KCE recommendations | | | |
|---|---|---|---|
| | | Level of agreement | |
| | | Yes | No |
| **45.** | Complementary interventions, such as omega-3 fatty acids, gluten-free, casein-free diet or chelation are not recommended to treat coexisting mental health problems in children with autism. | 100% | 0% |
| **Common medical and functional problems** | | | |
| **46.** | It is recommended to first offer a detailed clinical assessment in children with autism and sleep problems. | 100% | 0% |
| **47.** | 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. melatonine). | 100% | 0% |
| **48.** | Based on expert consensus feeding problems and eating behaviour deserve special attention in children with autism, and a multidisciplinary assessment should be performed to identify factors that matter. | 100% | 0% |
| **49.** | Biomedical interventions, such as multivitamins, omega-3 fatty acids, secretin and immunoglobulines are not recommended to treat common medical and functional problems in children with autism. | 100% | 0% |
| **Sexuality** | | | |
| **50.** | Based on expert consensus affective and sexual development deserves special attention in children with autism. | 100% | 0% |
| **51.** | Based on expert consensus adapted sexual education should be proposed to adolescents with autism. | 100% | 0% |

### *6.4.2. Round 2: level of agreement*

Number of participants= 13

**Table 30 – Associated features of autism and coexisiting conditions: Delphi round 2**

| Associated conditions : KCE recommendations | | Level of agreement | | |
|---|---|---|---|---|
| | | Yes | Yes | No |
| **Impairments in adaptive behaviour** | | | | |
| **new** | Based on parent's testimonials the GDG felt that a recommendatuion for PECS should be provided. | | 83% | 17% |
| **1.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairement in adaptive behaviour. | | 64% | 36% |
| **2.** | Pharmacological interventions, including Aripiprazole, are not recommended to treat impairment in adaptive behaviour in children with autism. | | 83% | 17% |
| **Speech and language problems** | | | | |
| **5.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend augmentative and alternative communication techniques such as PECS or RPMT for speech and language problems in children with autism. | | 67% | 33% |
| **8.** | There is insufficient evidence to recommend any type of behavioural or educational interventions to address speech and language problems in children with autism. | | 58% | 42% |
| **9.** | There is insufficient evidence to recommend parent training to address speech and language problems in children with autism. | | 58% | 42% |
| **IQ, academic skills and learning** | | | | |
| **22.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend specific social-communication interventions to improve IQ, academic skills and learning in children with autism. | | 92% | 8% |

### 6.4.3. Round 3: level of agreement

Number of participants= 11

**Table 31 – Associated features of autism and coexisiting conditions: Delphi round 3**

| Associated conditions : KCE recommendations | | Level of agreement Yes | No |
|---|---|---|---|
| **Impairments in adaptive behaviour** | | | |
| **1.** | Based on an evidence based approach, there is insufficient scientific evidence for behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairment in adaptive behaviour. Therefore no recommendation can be provided. | 90% | 10% |
| **2.** | Based on expert consensus the GDG provided a recommendation to use PECS for children with autism and impairment in adaptive behaviour . | 100% | 0% |
| **3.** | Pharmacological interventions are not recommended to treat isolated impairment in adaptive behaviour in children with autism. | 100% | 0% |
| **Speech and language problems** | | | |
| **4.** | There is insufficient evidence on the effect of behavioural or educational interventions on speech and language problems in children with autism. Therefore, no recommendation can be provided. | 82% | 18% |
| **5.** | There is insufficient evidence to recommend parent training to address speech and language problems in children with autism. | 80% | 20% |
| **6.** | Based on expert consensus the GDG recommended to involve parents when addressing speech and language problems in children with autism. | 100% | 0% |

*Two recommendations did not reach a level agreement at 85%*
*These recommendations are not kept and are deleted from the set of recommendations*

## 6.5. Interventions aimed at improving the impact on the family

### *6.5.1. Round 1: level of agreement and comments*

Number of participants= 12

**Table 32 – Interventions aimed at improving the impact on the family: Delphi round 1**

| Impact on the family: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | |
| | | Yes | No | |
| **Improving the impact on family** | | | | |
| **1.** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention to improve the impact on the family of children with autism. | 86% | 14% | if Evidence-based only means RCT ! |
| **2** | Based on expert consensus it is recommended to facilitate support for parents and to propose different support modalities. | 100% | 0% | |
| **3** | Based on expert consensus it is recommended that special attention be paid to signs of suffering and support seeking expressed by siblings and to propose different modalities to help. | 100% | 0% | |

## 6.6. Adverse events

### *6.6.1. Round 1: level of agreement and comments*

Number of participants= 12

**Table 33 – Adverse events: Delphi round 1**

| AUTISM:Adverse events: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement Yes | No | Comments |
| **1** | It is recommended to balance drugs benefits and risks prior to prescribing psychotropic medication. | 100% | 0% | |
| **2** | Parents should receive clear explanations on the expected benefit of the treatment and possible adverse events. | 100% | 0% | |
| **3** | It should be verified that the explanation was understood. | 100% | 0% | |
| **4** | Parents should be offered the possibility for continuous dialogue with the prescriber. | 100% | 0% | |
| **5** | Parents should be warned about the possibility of paradoxical reactions and know an action plan for seeking assistance. | 100% | 0% | |

## 6.7. Research recommendations

### *6.7.1. Round 1: level of agreement and comments*

Number of participants= 11

**Table 34 – Research recommendations: Delphi round 1**

| Research recommendations: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | *Comments on research recommendations* |
| | | Yes | No | |
| **1.** | The GDG recommends to promote community based research and to explore which research designs are best applicable to the population. | 100% | 0% | |
| **2.** | Given a limited but encouraging amount of evidence, the GDG recommends to focus research interventions on four domains: | | | |
| | 1. the Picture Exchange Communication System (PECS) | 100% | 0% | |
| | 2. the Learning Experience and Alternative Program for Preschools and their Parents (LEAP) | 100% | 0% | |
| | 3. the early Denver model | 91% | 9% | should be the Early Start Denver Model |
| | 4. the TEACCH model | 100% | 0% | |
| | 5. Speech and language therapy | 100% | 0% | |
| | 6. Psychopharmacological therapies for core features, challenging behaviour, associated features and coexisting conditions. | 100% | 0% | |

*The wording Early Start Denver Model was kept for the final set of recommendations*

## 6.8. Consensus statement applied to the Belgian context

### *6.8.1. Round 1: level of agreement and comments*

Number of participants= 11

**Table 35 – Consensus statement applied to the Belgian context: Delphi round 1**

| Belgian context: KCE recommendations | | | | |
|---|---|---|---|---|
| | | Level of agreement | | *Comments on research recommendations* |
| | | Yes | No | |
| **1.** | 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. | 100% | 0% | |
| **2.** | 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 | 100% | 0% | |
| **3.** | Care networks for children and young people with autism should be equally accessible to all. | 100% | 0% | |
| **4.** | Care networks should integrate adapted residential care for children and adolescents with autism who present challenging behaviour or are in a crisis situation. | 90% | 10% | This concept has several shortcomings: 1/ no (semi-quantitative)definition of challenging behaviour nor crisis -> parents and caretakers of hundreds of children with ASD may feel the need for external residential care, while there is no evidence that residential care is the best solution for all these children; 2/ taking children with ASD and challenging behaviour may lead to additional stress and worsening of the challenging behaviour. I and other professionals who deal with severe challenging behaviour in ASD, are more in favour of an intensive crisis-intervention system in the environment where the patient resides (home or existing residential care), while external residential care is limited to the extreme cases. |

| Belgian context: KCE recommendations | | | |
|---|---|---|---|
| | Level of agreement | | *Comments on research recommendations* |
| | Yes | No | |
| | | | I think we should be very very thoughtful about this issue, because it may have serious consequences on how services are organized, or not organized at all if our recommendation is too costly.<br><br>Clinical experience with this group leads me to think even further on the issue of who should take the responsibility of educating children with ASD and challenging behaviour. It's obvious that the model where it's all left to the parents does not work and is sometimes inhumane. At the other extreme, a model where the burden lies completely on the health care system, or is percieved as such, may lead to other situations that do not benefit the person with ASD (e.g. "dropping off at the emergency unit").<br><br>I do not know whether the KCE can make any suggestions in the area of who is responsible for what. Personally, I think we should made recommendations wich include some ethical thinking, and not only scientific evidence. |
| **5.** Education and schools catered to the needs of the children and young people with autism should be accessible to all. This also includes children with higher intellectual abilities than average. | 80% | 20% | **1)** In het nieuwe M-decreet is voorzien dat type 9 toegankelijk is voor alle kinderen met ASS behalve die groep die ook in aanmerking komt voor type 2. Ik dan deze redenering wel volgen en dat betekent dus dat ik niet akkoord kan gaan met bovenstaande stelling. 't Gaat er mij dus vooral om dat leerlingen met ASS die bijkomend een matig/ernstig/diep verstandelijke beperking hebben toch een andere aanpak vragen en die in de huidige vlaamse context best in type 2 krijgen en niet in het toekomstig type 9. Hoogbegaafde lln met ASS moeten uiteraard wel toegang kunnen krijgen tot type 9 en dat is ook voorzien. In de huidige regelgeving worden hoogbegaafde leerlingen |

| Belgian context: KCE recommendations | | | |
|---|---|---|---|
| | Level of agreement | | *Comments on research recommendations* |
| | Yes | No | |
| | | | eigenlijk ook niet 'gediscrimineerd'...maar ik was niet aanwezig op het overleg maandag...dus ik kan de aanleiding van de aanbeveling niet meteen plaatsen. **2)** if this is the only recommentadation with respect to schools it is a bit weird. It seems as if we promote more special education, while at least for children with higher intellectual abilities, we should strive for more inclusive schools |
| **6.** Professionals should be provided with adequate training and support. | 100% | 0% | |

### *6.8.2. Round 2: level of agreement*

Number of participants= 13

**Table 36 – Consensus statement applied to the Belgian context: Delphi round 2**

| Belgian context : KCE recommendations | | |
|---|---|---|
| | Level of agreement | |
| | Yes | No |
| **4.** 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. | 100% | 0% |
| **5.** 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. | 100% | 0% |

# 7. RESULTS OF THE SURVEY SUBMITTED TO THE STAKEHOLDERS

**Table 37 – Level of agreement and comments by stakeholders**

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **Domain 1: Organisation and delivery of care** | | | | | | | | | | |
| ***Organisation and delivery of care*** | | | | | | | | | | |
| **1** | All staff working with children and young people with autism should have an understanding of autism. | 100% | 0% | 26 | 26 | 26 | | | | *They should not only understand the diagnostic (behavioral) criteria but also and foremost the cognitive style in autisme, because that has an impact on communication and interaction, pivotal aspects of any education and treatment<br>* formation nécessaire pour tout professionnel<br>*Comprendre l'autisme! C'est un peu prétentieux car si c'était si simple, la présente étude n'aurait lieu d'être.<br>C'est quand on croit comprendre le psychisme qu'on est souvent dans l'erreur!*omdat een niet-aangepast aanpak veel spanning kan veroorzaken bij deze kinderen<br>*La question de la formation est essentielle. Elle doit également être critique et ouverte à différentes orientations théoriques.<br>*Cette compréhension de l'autisme doit se soutenir de différentes approches, cognitive, comportementale et psycho-dynamique. |
| **2** | In all settings, professionals should take into account the physical environment in which children and young people with autism are supported and cared for and make reasonable and appropriate adjustments. Where it is not possible to adjust or adapt the environment, processes should be adjusted to limit | 96% | 4% | 26 | 23 | 22 | 1 | 1 | 2 | *This depends on the level of the autism. It might be good to have a 'normal' environment so the children and young people learn to live in it.<br>*In some cases learning to live in a 'normal' environment could be usefull.<br>In other cases an adjustment is necessary.<br>*Il ne s'agit pas tant de limiter l'impact de l'environnement que de l'adapter, l'enrichir de telle manière que l'enfant autiste puisse l'utiliser |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | the negative impact of the environment | | | | | | | | | *D'accord si on entend par environnement également les relations aux soignants, qui doit rester respectueuse de la personne, de ses difficultés et de ses préférences.<br>*C'est incomplet. Les éléments cités sont importants mais il manque toute la dimension humaine et relationnelle. La manière de s'adresser à l'enfant est importante et le respect de ses propres choix. |
| **3** | Children and young people with autism should have access to a keyworker approach in order to manage and coordinate treatment, care and support, including the management of transitions, for the child or young person with autism and their family and carers. | 100% | 0% | 26 | 22 | 22 | | 1 | 3 | *at this moment there is not enough capacity so that each child with autism has access to a professionale setting for coordination and management<br>*This keyworker be available when asked for without a waiting list.<br>*Seulement sur demande de la famille ou de la personne, car cela limiterait la liberté de la personne et/ou de la famille dans ses décisions ultérieures<br>*Seulement sur demande de la famille ou de la personne, car cela limiterait la liberté de la personne et/ou de la famille dans ses décisions ultérieures<br>*Wanneer een kind met autisme bv op driejarige leeftijd in een revalidatiecentrum terechtkomt dan krijgt hij in ons centrum een 'trajectbegeleider'. We werken multidisciplinair: dus we zijn minstens met twee therapeuten , meestal drie. De trajectbegeleider is één van de therapeuten (logo, psycho, ergo of kiné). Deze houdt steeds het overzicht, neemt contact met de ouders, doet de schoolcontacten, neemt initiatieven,... . Ik vind dit een zeer goede werking. Wanneer het kind stopt in het revalidatiecentrum dan zou deze taak moeten overgenomen worden door een nieuwe trajectbegeleidier in de instelling, school of andere begeleidende dienst.<br>*The key worker should be accessed without a waiting list.<br>*j'ignore ce qu'on entend précisément par "keyworker" |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | *approche pluridisciplinaire nécessaire, et travail avec les parents*Je ne comprends pas ce que vous entendez par "keyworker"<br>*en lien avec les parents<br>*Accès, oui, mais obligation, non. il arrive que la relation avec le "keyworker" soit difficile, ou qu'il y ait désaccord sur l'orientation du travail. il est alors important que la personne ou ses parents puissent changer de référent.*Cette coordination ne doit pas être uniformisation. Il est important que la personne puisse avoir des partenaires différents, avec lesquels les enjeux sont différents. la collaboration entre eux est importante, certains savoir-faire peuvent se transmettre et se partager. mais la position de parents sera toujours autre que celle de médecin, d'enseignant ou d'éducateur. |
| **4** | Children and young people with autism should be offered evidence-based intervention aimed at preparation and coping strategies to facilitate access to community services, including the skills to access public transport, employment and leisure facilities. | 92% | 8% | 26 | 24 | 22 | 2 | | 2 | *The problem is to have access to these therapies, as a limited number of paramedics/school are trained in these techniques. Therefore, we have frequently to work with paramedics that are trained in non evidenced based techniques. Nevertheless, we see in our experience that these techniques are helping tremendously well in autistic children's<br>*Totally agree, but some interventions have not yet been studied enough to provide evidence...so, I would like to add 'research based' interventions<br>*Non- evidence-based intervertions as creative therapy, dnacetherapy, etc are valuable as well.<br>*Other non-evidence-based interventions (dance therapy, creative therapy, functionale therapy, equitherapy,...) are also usefull.<br>*not only the skills to 'public' transports<br>*Pas d'office. Il faut informer la personne autiste et/ou sa famille de l'existence de ces stratégies mais ce type |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | d'intervention ne peut être mis en place que sur demande et en connaissance de cause .<br><br>*Pas d'office. Il faut informer la personne autiste et/ou sa famille de l'existence de ces stratégies mais ce type d'intervention ne peut être mis en place que sur demande et en connaissance de cause .<br>*Het is natuurlijk moeilijk om alle interventies evidence-based te staven. Ik ben persoonlijk voorstander van een ontwikkelingsgerichte benadering met indien nodig gedragsmatige benadering. Waarom? Omdat ik dit gebruikt in mijn therapeutische setting. De ervaring leert mij dat dit goede resultaten geeft. Het is wel interessant dat een aantal programma's die echt niet goed zijn duidelijk worden benoemd en zo geëlimineerd worden.<br>*Het is niet altijd mogelijk om evidence-based te werken. Wel belangrijk is om bepaalde interventies die zeker niet werken of schadelijk zijn aan de kaak te stellen*But non-evidence based treatment are useful as well!<br>*Il n'existe pas d'intervention type valable pour tous les autistes!<br>*A) D'accord bien entendu qu'il faut travailler dans le sens de soutenir l'insertion sociale et faciliter l'accès aux services.<br><br>B) La notion même d' "évidence based intervention" est problématique. Ce n'est pas parce que dans des études statistiques un type d'intervention donne statistiquement de bons résultats qu'il doit être appliqué sans discernement à toutes les personnes dites "avec autisme".<br><br>il est important d'être informé de ces recherches et d'en |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | mesurer la pertinence au cas par cas.<br><br>*Sur le but, d'accord. Mais les outils à utiliser doivent rester modulables au cas par cas et selon le partenariat développé avec la personne.<br><br>Les dites "évidence based practice" sont tout aussi discutables et discutées que le DSM-5. il est important de maintenir le pluralisme dans la prise en charge des personnes autistes et de ne pas les réduire à leur comportement.<br>*But this is possible in a small number of patients in Brussels and Wallonia due to the lack of structures adapted |
| **5** | Children and young people with autism and their family and carers, should have easy access to short breaks, especially at periods of severe stress for the child and/or family. | 100% | 0% | 26 | 22 | 22 | | 1 | 3 | *This is important<br>*what is meant with 'short breaks'<br><br>- in school: not going to school during a certain periode?, at work, ...?<br>*what is meant with 'short breaks'?<br><br>at school: not going to school, staying home for a period of time<br>*This care should be easely to acces, not with a waiting list*Without a waiting list!!!<br>*Persoon die opvang doet, komt best uit het netwerk van de persoon met autisme<br>*OK pour les jeunes autistes et la famille, mais pas les travailleurs sociaux.<br>*OK pour les jeunes autistes et la famille, mais pas les travailleurs sociaux.*Il faut toutefois souligner que nous manquons cruellement de structures qui permettent actuellement aux familles et aux enfants cet accès à des |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | moments de pause.<br>*This acces should be without a waiting list*ceci n'est pas particulier à l'autisme mais à toutes les personnes handicapées et/ou avec problème de santé mentale |
| **6** | Children and young people with autism, and their family and carers, should be provided with post-diagnosis information about services available and support, for example a family support worker. | 100% | 0% | 26 | 25 | 25 | | | 1 | The need for this is striking and totally insufficient<br>*at this moment long waitling lists for family support<br>*And helped to acces this support.<br>*And get help to get this information or to get help to have the right help on the right place.<br>*Wanneer ouders in ons revalidatiecentrum terechtkomen dan worstelen vele ouders nog met de diagnose 'autisme'. Het aanvaarden van deze diagnose is voor veel ouders moeilijk. Dit heeft voor een aantal ouders tijd nodig. Een aantal ouders zijn wel bereid om informatie te krijgen. Maar zijn niet altijd bereid om in gesprek te gaan om samen oplossingen te zoeken voor problemen in de thuissituatie. Ook het aanvragen van thuisbegeleiding bij Victor is voor sommigen een grote stap. ( Ook jammer dat er een lange wachtlijst is) De ouders zouden nog beter moeten geïnformeerd moeten worden dat ze een dubbele weg moeten bewandelen: individuele begeleiding van het kind + begeleiding van het kind in de thuissituatie. Waarschijnlijk zit hier achter: angst voor het onbekende, angst voor kritiek,... In een revalidatiecentrum zou de ouderbegeleiding beter moeten uitgewerkt worden. Laagdrempelig beginnen (met info). Goede vergoeding (forfaits) voor de ouderbegeleiding. En misschien een mooie leidraad ontwikkelen hoe je de ouderbegeleiding aanpakt. Vanuit een reva: dus vanop afstand. En vanuit de thuisbegeleidingsdienst Victor. Ik zie ook weinig contacten en doorstroming van info tussen de reva's en Victor.<br>*Ok, fournir toutes les informations mais en laissant totale |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | liberté à la personne et à ses proches<br>*D'accord pour autant que cette information soit complète, donc donnant les coordonnées de TOUS les services existant, y compris les services ayant une approche psychodynamique<br>*Mais la question du diagnostic, n'est pas close pour autant; même si ce premier diagnostic reste la clef qui ouvre la voie à une prise en charge nécessaire (Ambulatoire, enseignement spécifique, institution, etc.) et à des aides.<br>*Need to better coordinate what exists<br>*Families need to be trained in order to have a coherent approach at home |
| **7** | Treatment and care of children and young people with autism should involve shared decision making and a collaborative approach that takes into account service user preferences. | 100% | 0% | 26 | 22 | 22 | | 1 | 3 | This work well, the problem is that there are not enough schools/centers trained to take autism in charge<br>*When the children or young people are able to understand and to discuss several points of vieuw.<br>*je ne comprends pas cette question<br>*D'accord pour autant que les préférences de l'usager ne soient pas obligatoirement comportementalistes.<br>*do'nt forget the parents |
| **8** | All children and young people with autism should have access to healthcare and social care services, including mental health services. Services should be adapted to the level of care specialisation the child needs. Services should be within a reasonable distance from their homes. Access should take the level of functional impairement into account but should not be restricted based on a child's intellectual ability, autism | 96% | 4% | 26 | 25 | 24 | 1 | | 1 | I agree with that, and it work fairly well for the moment.<br>*It would be better when the level of functioning of the children would be restricted to work in little groups where the heterogenity is not to much<br>*There is a need for groups where the children or young people have the same level of autism.<br>*Criteria should be made to have more heterogene groups<br>*extreme lack of these structures in brussels and wallonia |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | diagnosis, or any other eligibility criteria. | | | | | | | | | |
| ***Stakes and principles of action*** | | | | | | | | | | |
| **9** | A coherent multidisciplinary approach is needed. | 100% | 0% | 26 | 24 | 24 | | 1 | 1 | *La multidisciplinarité ne semble pas indispensable dans tous les cas. Mais elle l'est à pratrir d'un certain niveau de gravité des troubles.<br>*Ik denk dat de huidige reva's hier beter en beter werk verrichten. Multi: dokter, logo, psy, ergo en kiné. Ze kunnen hier al vanaf peuter terecht. Plus de combinatie begeleiding in reva en naar school gaan in het gewone onderwijs verloopt goed. Ook zie ik dat er meer en meer GON-begeleiders zijn in het gewone onderwijs. Dit alles verhoogt de kans dat het kind met ASS in het gewoon onderwijs kan functioneren.<br>*La multidisciplinariité comprend également la possibilité multiréférentielle et la liberté de l'organiser; |
| **10** | Define a framework and quality criteria for multi (trans) disciplinary approach in the same or in different institutions. | 95% | 5% | 26 | 22 | 21 | 1 | 3 | 1 | Need for a Medical Doctor and paramedics (speech therapist, physiotherapist, ergo therapist, social worker) trained with autism<br>*Il est important d'avoir un plan d'ensemble cohérent qui articule les interventions. Cela n'implique pas que toutes les institutions et tous les thérapeutes doivent faire la même chose. Une institution de soins n'a pas le même rôle qu'une école spécialisée. Les soins de 1ère, 2e et 3e ligne sont différents, etc...<br>*in the same OR in different institutions: what is meant?<br>*based on the functional level of the children/young people<br>*Si les critères de qualité ne se réfèrent qu'à un seul type d'approche ce n'est pas de la qualité mais des critères de corporation.<br>*il s'agit bien d'un cadre et non d'une imposition quand au contenu du travail, ce qui aurait pour effet de ne plus |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | pouvoir s'adapter à la situation et à la singularité de chaque cas. Et donc d'empêcher ses inventions de se déployer.<br>*I generally agree, but the term 'framework' can be interpreted differently. |
| **11** | A therapeutic team should establish a framework for an individualized work plan and should identify a coordinator. | 100% | 0% | 26 | 24 | 24 | | | 2 | *nice RC, but achievable?<br>*Het is belangrijk dat de coördinator iemand is die al werkt met de persoon met autisme en niet nog iemand nieuw is die erbij komt<br>*C'est une bonne façon de procéder lorsque l'enfant est accueilli dans un centre, mais il est important de laisser la liberté aux familles de gérer leur enfant autiste comme ils le souhaitent pendant les moments passés à la maison. Le plan de travail individualisé a des limites qui sont celles du respect de la vie des familles.<br>*C'est une bonne façon de procéder lorsque l'enfant est accueilli dans un centre, mais il est important de laisser la liberté aux familles de gérer leur enfant autiste comme ils le souhaitent pendant les moments passés à la maison. Le plan de travail individualisé a des limites qui sont celles du respect de la vie des familles.<br>*In mijn revalidatiecentrum hebben wij voor elk kind een trajectbegeleider. Dit is één van de therapeuten. Dit vind ik persoonlijk zeer belangrijk omdat je het kind enkel echt kan kennen en begrijpen als je met het kind werkt. Zo kan je alles vanuit de noden van het kind coördineren en de nodige initiatieven nemen. Er is natuurlijk geregeld overleg nodig met de betrokken therapeuten, ouders en school, CLB,ev. GON en ev. thuisbegeleiding. De vraag is wie neemt hier de overkoepelende coördinatie op zich?<br>*And evaluate this framework and adapt it when necessary<br>*"individualized work" est une terme qui fait référence au |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | comportementalisme. Il faut effectivement définir un cadre de prise en charge mais quelle que soit l'orientation choisie par les parents<br>*Formulée ainsi, la proposition est attirante mais qu'entendez-vous par coordinateur?<br>*therapeutic does'nt mean medical !<br>*Un cadre de travail explicite est indispensable, tout en laissant la place à l'invention de la personne et de ses accompagnants.<br>*Same comment here. |
| **12** | A framework and quality criteria should be formalised within an institution, in conventions with other professionals, in networks. | 91% | 9% | 26 | 22 | 20 | 2 | 1 | 3 | *what is meant with 'an institution'<br>*What is meant with 'an institution': an hospital, a school for children with autism, a VAPH institution, ...<br>*OK pour que ces critères soient formalisés dans l'institution qui accueille le jeune.<br><br>Mais les conventions avec d'autres professionnels engagent les parents dans des réseaux, et il est nécessaire préalablement qu'ils puissent donner leur accord pour que des infos qui concernent leur enfant soient diffusées de cette manière.<br>*Il faudrait que les réseaux mis en place restent ouverts à tous les intervenants, quelle que soit leur orientation, et qu'une réelle collaboration soit mise en place<br>*La proposition n'est pas claire ou très, trop tendancieuse<br>*en accord avec le pouvoir subsidiant , les familles , ...<br>*idealiter!<br>*OK pour "critères de qualité", s'ils respectent la liberté thérapeutique et la diversité des pratiques.<br>*Un cadre d'orientation, pas une prescription qui enferme.<br>*Same comment here. |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **13** | The framework and quality criteria should be known by all professionals. | 91% | 9% | 26 | 23 | 21 | 2 | | 3 | *... et doivent être communiqués aux parents.<br>*Il faut d'abord définir ce qu'on appelle « cadre et critères de qualité » afin que cela ne débouche pas sur un contrôle et un jugement des institutions entre elles ou par une instance extérieure.<br>*Il faut d'abord définir ce qu'on appelle « cadre et critères de qualité » afin que cela ne débouche pas sur un contrôle et un jugement des institutions entre elles ou par une instance extérieure.<br>*Interessant zou zijn dat het digitale dossier van het kind met autisme door alle betrokkenen te raadplegen is en door allen up to date te houden.<br>*Tous les professionnels ne travaillent pas avec des grilles de lecture. Il est donc difficile de comparer le cadre et les critères<br>*Maintenir une cohérence entre les professionnels*Cfr questions 12 et 10.<br><br>Si les critères de qualité sont multiréférentiels, je suis d'accord que chaque service rende public ses propres critères de qualité<br>*idealiter!<br>*Same comment here. |
| **14** | The personalised educational plan should reflect the framework and quality criteria. | 96% | 4% | 26 | 24 | 23 | 1 | | 2 | *Le terme « plan éducatif personnalisé » présuppose une orientation cognitivo-comportementaliste de la prise en charge.<br><br>Or il existe d'autres orientation de grande qualité et les parents dévraient avoir le choix à chaque étape de l'évolution de leur enfant.<br>*Le terme « plan éducatif personnalisé » présuppose une orientation cognitivo-comportementaliste de la prise en charge. |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | Or il existe d'autres orientation de grande qualité et les parents dévraient avoir le choix à chaque étape de l'évolution de leur enfant.<br>*Opletten dat het niet te theoretisch wordt. En dat het te omslachtig is. Dat je te veel lijstjes moet overlopen. Belangrijk is een goede omschrijving van hoe het kind functioneert en wat de therapie-inhoud is en jaarlijkse omschrijving van de evolutie.<br>*Ces termes font référence à l'orientation comportementaliste. Or d'autres modes de prise en charge conviennent très bien et donnent de bons résultats..<br>*cfr questions 10, 11, 12, 13<br>*Same comment here. |
| ***Tools for improving coherent intervention*** | | | | | | | | | | |
| **15** | Develop a personalised program based on evaluation with appropriate tools and on observation in daily life, and in agreement with the patient, the parents and all professionals involved. | 96% | 4% | 26 | 24 | 23 | 1 | | 2 | *La multidisciplinarité ne semble pas indispensable dans tous les cas. Mais elle l'est à pratrir d'un certain niveau de gravité des troubles.<br>*Ik denk dat de huidige reva's hier beter en beter werk verrichten. Multi: dokter, logo, psy, ergo en kiné. Ze kunnen hier al vanaf peuter terecht. Plus de combinatie begeleiding in reva en naar school gaan in het gewone onderwijs verloopt goed. Ook zie ik dat er meer en meer GON-begeleiders zijn in het gewone onderwijs. Dit alles verhoogt de kans dat het kind met ASS in het gewoon onderwijs kan functioneren.<br>*La multidisciplinariité comprend également la possibilité multiréférentielle et la liberté de l'organiser; |
| **16** | Assign the task of coordinator to one of the professionals (not necessarily an MD) in order to guarantee the coherence and continuity of care. | 96% | 4% | 26 | 23 | 22 | 1 | 1 | 2 | Need for a Medical Doctor and paramedics (speech therapist, physiotherapist, ergo therapist, social worker) trained with autism<br>*Il est important d'avoir un plan d'ensemble cohérent qui |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | articule les interventions. Cela n'implique pas que toutes les institutions et tous les thérapeutes doivent faire la même chose. Une institution de soins n'a pas le même rôle qu'une école spécialisée. Les soins de 1ère, 2e et 3e ligne sont différents, etc...<br>*in the same OR in different institutions: what is meant?<br>*based on the functional level of the children/young people<br>*Si les critères de qualité ne se réfèrent qu'à un seul type d'approche ce n'est pas de la qualité mais des critères de corporation.<br>*il s'agit bien d'un cadre et non d'une imposition quand au contenu du travail, ce qui aurait pour effet de ne plus pouvoir s'adapter à la situation et à la singularité de chaque cas. Et donc d'empêcher ses inventions de se déployer.<br>*I generally agree, but the term 'framework' can be interpreted differently. |
| **17** | A person who had a comprehensive training (including all the important aspects of ASS) will be responsible for overseeing and/or delegating the coordination task. | 100% | 0% | 26 | 16 | 16 | | 6 | 4 | *nice RC, but achievable?<br>*Het is belangrijk dat de coördinator iemand is die al werkt met de persoon met autisme en niet nog iemand nieuw is die erbij komt.<br>*C'est une bonne façon de procéder lorsque l'enfant est accueilli dans un centre, mais il est important de laisser la liberté aux familles de gérer leur enfant autiste comme ils le souhaitent pendant les moments passés à la maison. Le plan de travail individualisé a des limites qui sont celles du respect de la vie des familles.<br>*C'est une bonne façon de procéder lorsque l'enfant est accueilli dans un centre, mais il est important de laisser la liberté aux familles de gérer leur enfant autiste comme ils le souhaitent pendant les moments passés à la maison. Le plan de travail individualisé a des limites qui sont |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | celles du respect de la vie des familles.<br>*In mijn revalidatiecentrum hebben wij voor elk kind een trajectbegeleider. Dit is één van de therapeuten. Dit vind ik persoonlijk zeer belangrijk omdat je het kind enkel echt kan kennen en begrijpen als je met het kind werkt. Zo kan je alles vanuit de noden van het kind coördineren en de nodige initiatieven nemen. Er is natuurlijk geregeld overleg nodig met de betrokken therapeuten, ouders en school, CLB,ev. GON en ev. thuisbegeleiding. De vraag is wie neemt hier de overkoepelende coördinatie op zich?<br>*And evaluate this framework and adapt it when necessary<br>*"individualized work" est une terme qui fait référence au comportementalisme. Il faut effectivement définir un cadre de prise en charge mais quelle que soit l'orientation choisie par les parents<br>*Formulée ainsi, la proposition est attirante mais qu'entendez-vous par coordinateur?<br>*therapeutic does'nt mean medical !<br>*Un cadre de travail explicite est indispensable, tout en laissant la place à l'invention de la personne et de ses accompagnants.<br>*Same comment here. |
| **18** | A file (case record, dossier) is the source document for communication between professionals. | 96% | 4% | 26 | 24 | 23 | 1 | 1 | 1 | *what is meant with 'an institution'<br>*What is meant with 'an institution': an hospital, a school for children with autism, a VAPH institution, ...<br>*OK pour que ces critères soient formalisés dans l'institution qui accueille le jeune.<br><br>Mais les conventions avec d'autres professionnels engagent les parents dans des réseaux, et il est nécessaire préalablement qu'ils puissent donner leur accord pour que des infos qui concernent leur enfant |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | soient diffusées de cette manière.<br>*Il faudrait que les réseaux mis en place restent ouverts à tous les intervenants, quelle que soit leur orientation, et qu'une réelle collaboration soit mise en place<br>*La proposition n'est pas claire ou très, trop tendancieuse<br>*en accord avec le pouvoir subsidiant , les familles , ...<br>*idealiter!<br>*OK pour "critères de qualité", s'ils respectent la liberté thérapeutique et la diversité des pratiques.<br>*Un cadre d'orientation, pas une prescription qui enferme.<br>*Same comment here. |
| **19** | The file should contain all relevant information on the person with autism: personalised project, evaluations, treatment and educational plan, specific interventions. | 91% | 9% | 26 | 23 | 21 | 2 | 1 | 2 | *... et doivent être communiqués aux parents.<br>*Il faut d'abord définir ce qu'on appelle « cadre et critères de qualité » afin que cela ne débouche pas sur un contrôle et un jugement des institutions entre elles ou par une instance extérieure.<br>*Il faut d'abord définir ce qu'on appelle « cadre et critères de qualité » afin que cela ne débouche pas sur un contrôle et un jugement des institutions entre elles ou par une instance extérieure.<br>*Interessant zou zijn dat het digitale dossier van het kind met autisme door alle betrokkenen te raadplegen is en door allen up to date te houden.<br>*Tous les professionnels ne travaillent pas avec des grilles de lecture. Il est donc difficile de comparer le cadre et les critères<br>*Maintenir une cohérence entre les professionnels*Cfr questions 12 et 10.<br><br>Si les critères de qualité sont multiréférentiels, je suis d'accord que chaque service rende public ses propres critères de qualité |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | *idealiter!<br>*Same comment here. |
| **20** | Sharing the file necessitates parental consent, in line with the rules of duty of professional confidentiality. | 96% | 4% | 26 | 23 | 22 | 1 | 1 | 2 | *Le terme « plan éducatif personnalisé » présuppose une orientation cognitivo-comportementaliste de la prise en charge.<br><br>Or il existe d'autres orientation de grande qualité et les parents dévraient avoir le choix à chaque étape de l'évolution de leur enfant.<br>*Le terme « plan éducatif personnalisé » présuppose une orientation cognitivo-comportementaliste de la prise en charge.<br><br>Or il existe d'autres orientation de grande qualité et les parents dévraient avoir le choix à chaque étape de l'évolution de leur enfant.<br>*Opletten dat het niet te theoretisch wordt. En dat het te omslachtig is. Dat je te veel lijstjes moet overlopen. Belangrijk is een goede omschrijving van hoe het kind functioneert en wat de therapie-inhoud is en jaarlijkse omschrijving van de evolutie.<br>*Ces termes font référence à l'orientation comportementaliste. Or d'autres modes de prise en charge conviennent très bien et donnent de bons résultats..<br>*cfr questions 10, 11, 12, 13<br>*Same comment here. |
| **21** | In professional communication, it is recommended to use the DSM-5 classification. | 59% | 41% | 26 | 17 | 10 | 7 | 6 | 3 | *Il faut en tout cas un système de classification qui garantit que "tout le monde" parle le même langage. Tout le monde = les thérapeutes entre eux, les thérapeutes et les parents, les thérapeutes et les chercheurs, etc.<br>*at tis moment still using DSM-IV<br>*at this moment, still using DSM-IV*Of course, if a DSM-5 |

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| | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | classification has been made...<br>*This is not enouhg, some other information can help also.<br>*Actuellement nous utilisons plutôt l'ICD 10 qui nous paraît plus complet dans son approche des T.E.D.<br>*I prefer the story of a person! not the symptoms<br>*POURQUOI choisir le DSM V alors qu'en ce qui nous concerne, nous travaillons plutôt avec l'ICD 10 la version 11 devrait sortir bientôt. l'INAMI nous demande d'ailleurs de donner les références ICD 10 pour les groupes de pathologies que nous prenons en charge et c'est ce que nous faisons actuellement.<br>*Het boek 'Doe kijk luister zeg' van Kathleen Ann Quill is een zeer goed boek. Dit zou een basisboek kunnen zijn voor therapeuten.<br>*But this should not be the only source of information, there is a lot of information needed that we cannot find in DSM 5 classification<br>*Il s'agit d'une classification médicale, or l'autisme a été reconnu comme un handicap. Il faut savori ce que l'on veut!<br>*no consensus about the description of each pathology in DSM 5<br>*Le DSM 5 provoque une hémorragie du spectre des troubles autistiques et définit comme pathologique des phénomènes ou des vécus qui font partie de la vie "ordinaire" humaine.<br>*and/or WHO international classification*voorlopig is DSM-V nog niet geïmplementeerd in het werkveld, mogelijks in de toekomst<br>*Le DSM-5 est critiquable et critiqué par ceux-là même qui ont contribué aux éditions précédentes. Dans la communication entre professionnel, le diagnostic DSM |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | peut être un élément d'information mais il est très pauvre. Encore une fois, il faudrait plus mettre l'accent sur les intérêts, les compétences, les atouts, les émergences de la personne, pour pouvoir assurer ainsi une continuité du travail dont le centre est la personne elle-même et non l'évaluation.<br><br>Rien dans le DSM ne permet d'orienter le travail. Ce type de diagnostic permet tout au plus un classement qui peut être utilisé pour décider d'un cadre de prise en charge (entrée en institution par exemple.) mais il ne peut à lui-seul aucunement orienter le travail.<br>*I generally agree, but I think there first should be agreement about how to deal with differences between DSM-IV-TR and DSM-5.<br>*DSM 4 or 5 are fine<br>*It depends on what is communicated to whom |
| **22** | A go-between notebook or electronic tool is recommended to support communication between the professionals and the parents and child. | 83% | 17% | 26 | 23 | 19 | 4 | 2 | 1 | *should the coordinator be available at each moment the risk with electronic tool?<br>*This is usefull for children, for young people it might feel like a threat.<br>*Begrijpbare taal ook voor ouders is belangrijk<br>*Je ne sais pas si la communication doit obligatoirement passer par un support électronique, mais je suis d'accord pour dire qu'il est indispensable qu'existent des communications fréquentes entre les différents intervenants, les parents et l'enfant et qu'un cahier de liaison est le plus souvent une nécessité facilitant cette communication.<br>*In ons revalidatiecentrum wordt steeds een heen- en weerschriftje gebruikt. Dit wordt op het moment van therapie ingevuld. Ik vind dit beter dan bv. mail. Ik heb geen tijd om nadien naar iedereen een mail te sturen. Dit |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | is niet realistisch. Het heen-en weerschriftje werkt goed: ook belangrijke mededelingen worden er in opgeschreven, bv. schooluitstap, info van de ouders. Het zou goed zijn moest ook de GON hier geregeld iets in schrijven: dit gebeurt eigenlijk al vaak. Ook de telefoonnr., mailadressen van de betrokkenen staan er in. Als er iets belangrijks is wordt er gemaild of gebeld. *Beste is een heen-en weerschriftje dat je op het einde van de individuele therapie kan invullen. Wij hebben geen tijd om later nog elektronisch info door te geven. Voor groepstherapieën: geen tijd om voor iedereen zulk een schriftje in te vullen. Daarvoor zou je iets elektronisch kunnen opstellen of geregeld info van een aantal sessies samen in het schriftje plakken. *In some cases this is recommended, in other cases (when there is a difficult social system) a notebook is not recommended but it should be accompanied by a professional. For young people a notebook is not always necessary *Recommandé oui, mais des exceptions doivent pouvoir être acceptées. *It dépends on the educational or social level of the parents*L'informatique est la meilleure mais peut aussi être la pire des choses. Un dossier informatique, d'accord mais ne s'apparente pas à un QCM! *ce système doit être transparent *dit is voor bepaalde kinderen en ouders een goed hulpmiddel, maar is geen must voor iedereen |
| **23** | Upon transfer between institutions (medical/social) a contact person (referent) should be kept until integration for the child and his family is ensured. | 95% | 5% | 26 | 22 | 21 | 1 | 2 | 2 | *Ca fait 4 fois qu'on revient sur un coordinateur-référent.(RC 11, 16, 17) Pourquoi pas si c'est le choix des parents? Mais sera-t-il possible de changer de référent dans le cas où un désaccord important empêche une bonne collaboration? En ce qui concerne les enfants pris |

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| | | | | | | | | | | en charge en institution, et à l'école, ce travail est déjà assumé par les AS et les PMS. Chaque intervenant, institution, médecin, etc; est responsable du passage vers un autre intervenants et de s'informer de ce qui a pu se construire auparavant. |
| **24** | Networking, collaboration and regular meetings should be organized between professionals. | 100% | 0% | 26 | 24 | 24 | | 1 | 1 | *But who is going to be in charge of this network??<br>*when this is possible in time.<br>*De vraag is: Waar vindt dit plaats? Diegene die zich moet verplaatsen moet daar tijd en geld voor krijgen!<br>*Il faut préciser "regular".<br>*Cela se fait déjà régulièrement et s'intensifie depuis quelques années en Wallonie.<br>*en y associant les familles chaque fois que c'est nécessaire<br>*and parents |
| **25** | The Reference centres for Autism have a specific role in supporting the networking. | 82% | 18% | 26 | 17 | 14 | 3 | 5 | 4 | *professionals can contact each other so information can be transfered.<br>*Permettez-moi d'insister sur le fait que les centres de référence doivent être en mesure de donner aux parents qui les consultent l'ensemble des coordonnées de TOUS les centres qui peuvent venir en aide à leurs enfants, y compris ceux qui ne dépendent pas forcément de l'université dont ils dépendent.<br>*referentiecentra?<br>*pas nécessairement<br>*Je pense que OUI et c'est bien dans ce sens que j'ai toujours soutenu et encouragé la mise en place de cette structure au sein de notre région. J'attire toutefois l'attention de tous sur le fait qu'il est important qu'une structure de ce type renseigne l'ensemble des centres d'intervention thérapeutiques qui peuvent aider un enfant ou adolescent avec autisme. IL est arrivé plusieurs situations ou des parents n'avaient pas été avertis de |

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| | | | | | | | | | | l'existence de centres d'interventions thérapeutiques qui auraient pu leur venir en aide alors qu'on leur avait renseigné d'autres structures existantes dans la même région. Question de pouvoir organisateur ? ... il s'agit d'un problème sans doute local mais qui mérite d'être souligné.<br>*Op geregelde basis vorming geven, verplicht voor alle betrokken instanties. Als je dit samen doet zou je ook goed kunnen netwerken en beter op mekaar kunnen afstemmen in een andere omgeving.<br>*And should get the support (financial and with enough professionals) to be able to do this work<br>*what does mean "specific role" and which tasks does it cover ?<br>*Cette formulation est trop vague. Qu'entendez-vous par "rôle spécifique"? Un rôle de conseiller, un rôle se substituant aux cliniciens qui accompagnent l'autiste?...<br>*Encore faut-il qu'ils en aient les moyens et qu'ils soient ouverts à des approches différentes et aux points de vue nécessairement différents entre les professionnels qui voient la personne en individuel en situation de testing et et ceux qui accompagnent la personne au quotidien.<br>*CRA with a good knowledge of autism are doing also a great job and treat several autistic patients with excellent results. With the change of the rules in 2015, these patients will not be able too be treated any more by these centres? It should be interesting for the patients to be able to treat these patients still there, with eventually the supervision of reference centers for autism<br>* Specific but exclusive |
| **26** | Institutions, especially hospitals, should offer protocols to facilitate first contacts. | 75% | 25% | 26 | 20 | 15 | 5 | 3 | 3 | *Je ne suis pas sûr de comprendre la question. De quels 1ers contacts s'agit-il? Entre le patient et l'institution?<br>*facilatation of first contacts is O.K. |

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| | | | | | | | | | but also a triage for first, second en third line support has to be made<br>*facilitation of first contacts is important<br><br>but also the triage of first, second and third line service*But, what is in the protocol??<br>*Ik heb momenteel een kindje met ASS in behandeling: gestart vanaf 2° kleuter. Dus vrij late aanmelding. Mama vertelde mij dat het kindje als baby zware voedingsproblemen had. Het wou de eerste drie maanden na de geboorte niet eten: opgenomen in Gent. Daar hebben ze toen tegen mama gezegd: dit zien we vaak bij kinderen met ASS. De ouders zouden op dat moment een folder moeten krijgen met info en contactadressen voor als ze later stappen willen zetten naar het stellen van een diagnose<br>*But should look at the individuals and sometimes decide not to follow a protocol when this would be negative for the child or young people<br>*These protocols would include advices of different professionals*Que les hôpitaux distillent des informations facilitant les contacts, OK. Mais une fois de plus, qu'entendez-vous par protocole? c'est beaucoup trop allusif comme formulation. On sait par ailleurs qu'on ne rentre jamais totalement dans le cadre d'un protocole<br>*le danger du protocole est de mettre les personnes dans des cases , par contre un support pour les premiers contacts est nécessaire<br>*as for all patients<br>*er moet ook de flexibiliteit zijn om in te spelen op een minder "reguliere" aanmelding bvb. crisisaanmelding of aanmelding van een kind met zeer belangrijke comorbide |

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| | | | | | | | | | | pathologie en dit biedt een protocol niet steeds<br>*Il y a bien sûr un cadre par défaut, et il est explicité aux parents mais trop de protocole tue l'invention. Il faut laisser place à la rencontre et accueillir la manière particulière de la famille et de l'enfant de se présenter. C'est extrêmement enseignant et plus accueillant que de suivre un protocole rigide. La suite des démarches peut être alors adaptée aux besoins et demandes spécifiques de l'enfant et de ses parents.<br>*If that protocols have some flexibility; protocols must remain patient-centered and not standardized, because persons with ASS are all different |
| **27** | A medical examination by a medical doctor familiar with autism and chosen by the parents should be offered at the start of the screening and whenever needed. | 91% | 9% | 26 | 23 | 21 | 2 | 2 | 1 | *In a hospital a specialized doctor is available.<br>*De inbreng van de ouders is belangrijk en wordt best meegenomen<br>*Ook de dokter zou zijn verslag elektronisch moeten kunnen bijvoegen tot het dossier.<br>*Chosen by the parents or the available doctor in a hospita<br>*niet standaard voor iedereen, op indicatie<br>*not clear to me what the exact role of this MD would be. |
| ***Sensitive transition periods*** | | | | | | | | | | |
| **28** | Diagnostic and therapeutic teams should collaborate closely. Professionals who intervene only occasionally should consult the team. | 95% | 5% | 26 | 22 | 21 | 1 | 3 | 1 | *'Must consult " instead of should consult<br>*<br>Consult the coördinator of the team<br>*Bij eerste aanmelding (in reva) is het ideaal als diagnostisch en therapeutisch team in dezelfde dienst zit.<br>*for increasing the coherence between professionals<br>*Cette formulation est à soutenir que si les professionnels ne sont pas dans un rapport de subordination. La collaboration doit garantir et préserver la liberté thérapeutique.<br>*Statement not clear to me. |

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| **29** | Participation of representatives of therapeutic teams should be offered to parents early on during the information sessions on the diagnosis. | 96% | 4% | 26 | 23 | 22 | 1 | | 3 | *achievable?<br>after diagnosis often al waiting list before access to treatment and support<br>*however there is often a long waiting list befeore starting therapeutic support<br>Is it acheivable the a therapeutic team is already involved during the daignositc assessment ??<br>*Les pratiques en matière de remise du diagnostic aux parents ou aux familles peuvent être variables selon les institutions, il n'est pas toujours possible de remettre le diagnostic en présence de tous les intervenants des différentes équipes thérapeutiques mais il est clair que les parents doivent pouvoir être mis en contact avec les intervenants des différentes équipes thérapeutiques, surtout si un projet d'intervention thérapeutique est proposé ensuite.<br>*Je m'interroge sur la pertinence d'imposer la présence de représentants de plusieurs disciplines lors des premières séances d'information du diagnostic. Si cela peut paraître intéressant, il n'en reste pas moins que l'annonce du handicap est une étape parfois très délicate et nécessite beaucoup de tact. La multiplication des intervenants peut ne pas faciliter la communication avec les parents et entrainer une dispersion des informations qui pourrait être préjudiciable à une bonne compréhension. Je crois aussi que cette possibilité n'est pas forcément possible dans toutes les structures. C'est une question délicate pour laquelle je préférais une grande prudence, laissant la porte ouverte à cette possibilité sans l'imposer.<br>*OK si les "therapeutic teams" comprennent des représentants de toutes orientations<br>*Cela peut être intéressant mais me paraît peu réaliste |

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| | | | | | | | | | | tenant compte des listes d'attente dans les services. de plus, ces rencontres "tripartites" devraient être financées.<br>*avec la capacité d'utiliser des termes compréhensibles pour les familles<br>*Ca ne me semble pas faisable. Sauf si l'équipe thérapeutique est de la même institution, le même hôpital par exemple. S'il s'agit d'un centre de jour ou d'une école, je ne vois pas comment cela serait organisable. De plus une transparence absolue entre les différents acteurs n'est pas souhaitable, même s'il est nécessaire que chacun des intervenants rende compte de son travail. |
| **30** | Transition periods e.g. transfer from one type of care/education to another or from childhood to adulthood require particular attention and should be prepared. Continuity of care should be assured. | 100% | 0% | 26 | 25 | 25 | | | 1 | *Very important!<br>*Ceci est une évidence et se fait déjà de manière très attentive de la par des institutions que je connais et avec qui je collabore depuis plus de 35 ans. Nous savons combien le changement d'institution, d'environnement est susceptible de réveiller une angoisse importante chez ces enfants et adolescents. Un accompagnement est essentiel!<br>*Mais il manque cruellement de place!<br>*New places to take care of autistic patients is urgently needed |
| **31** | Crisis situations require specific evaluation and intervention. Necessary information should be communicated among professionals, also in case hospitalization is inevitable. Specific education of professionals about crisis situations is necessary. | 96% | 4% | 26 | 24 | 23 | 1 | 1 | 1 | *And crisis should be available without a waiting list, in a good environment<br>*Par définition les professionnels répondent à des situations de crise.<br>*Ce qui est primordial lorsqu'il y a crise, c'est de reconnaître le "bien fondé" des manifestations de l'enfant, de repérer et d'entendre que la crise ne vient pas de rien et qu'il ne s'agit pas simplement d'éradiquer les expressions de crise;<br>*l'évaluation doit tenir compte de la famille*why not training ? |

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| | | | | | | | | | | *En réalité, quand une observation hospitalière est nécessaire, nous ne trouvons pas de place et ce sont alors les parents qui doivent assumer l'arrêt temporaire de prise en charge. Et ceci est inacceptable. |
| ***Education and support for professionals*** | | | | | | | | | | |
| **32** | Continuous education (at least every 2 to 3 years) is needed for all professionals. | 96% | 4% | 26 | 24 | 23 | 1 | 1 | 1 | *Au moins quelques heures par an de mise à jour des connaissances, en fonction de l'évolution de la recherche scientifique.<br>*Op de hoogte brengen van de recente ontwikkelingen is vooral belangrijk + is niet voor iedereen in dezelfde mate nodig<br>*Une formation prévue tous les 2 ou 3 ans n'est pas suffisante lorsqu'on est face à des enfants très perturbés comme bon nombre d'autistes. La formation doit être permanente, si on veut qu'elle ne soit pas que "technique". On sait que la dimension relationnelle est bien plus importante que la seule technique;<br>*C'est même un minimum! Une formation continue est souhaitable, avec des moments de formation plus intensifs au moins une fois par an.<br><br>Ces formations doivent ouvrir le professionnel à différentes approches et outils cliniques, éducatifs et thérapeutiques. |
| **33** | Therapeutic teams should be accompanied by an external expert (representing a reference centre for autism) for debriefings once per year. | 53% | 47% | 26 | 19 | 10 | 9 | 6 | 1 | *there exists therapeutic teams with enough experience, who do not necessary need yearly meeting wiht an external expert of a reference centre for autism<br>*There are therapeutic teams who have enough experience and do not need a yearly debriefing with RCA<br>*Why limit this to people representing a reference centre for autism? Why not "an external expert with enough credentials to prove his/her expertise"? See the model of SEN, the expertise networks... |

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| | | | | | | | | | *Teams should be educated on the theme where they feel to have a lack of knowledge.<br>*Notre centre est dans une situation particulière puisque cela fait presque 40 ans que nous nous sommes penchés sur l'approche thérapeutique des enfants avec autisme et que nous avons acquis dans ce domaine une expertise que le centre de référence autisme régional ne peut pas avoir actuellement. Il n'empêche que nous restons évidemment très ouvert à la communication avec un représentant de ce centre de référence chaque fois que cela s'avère souhaitable et nous gardons une excellente collaboration avec les autres services d'intervention. Il est probable qu'il s'agit là d'une situation tout à fait atypique et spécifique.<br>*RC 34 is enough<br>*Je voudrais préciser ici que dans notre structure spécifique: le Centre Henri Wallon, nous prenons en charge des enfants avec autisme depuis plus de 40 ans. Nous avons poursuivi de nombreuses recherches pour ajuster nos interventions thérapeutiques, nous avons au sein même de notre établissement 10 journées de formation par an, au cours desquelles nous faisons intervenir des spécialistes extérieurs pour nous familiariser avec les notions en évolution. Le Centre de référence Autisme Liège est certes composé de personnes compétentes mais nous organisons au sein de notre établissement des réunions de debriefings qui sont coordonnés par les thérapeutes les plus anciens et les plus chevronnés qui ont d'ailleurs reçus une formation spécifique à cet effet. De ce fait, je ne suis pas certain qu'il soit indispensable de faire appel une fois par an à un expert extérieur pour faire ce débriefing. Toutefois, c'est évidemment quelque chose pour lequel nous restons |

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| | | | | | | | | | ouvert et c'est une pratique que nous sommes tout à fait en mesure de réaliser quand un enfant que nous suivons est passé par le Centre de Référence Autisme Liège. On sait aussi qu'étant donné le nombre de cas qu'ils suivent, il leur est difficile d'assurer un suivi annuel de tous les cas qui consultent chez eux. Donc ma question est: faut-il tenter d'imposer l'accompagnement par un expert extérieur ?<br>*Teams can ask for an external expert when needed<br>*Les professionnels doivent avoir accès à des formations et des supervisions. Il ne faut pas que cet accompagnement devienne une main mise sur le travail des professionnels.<br>*Bien plus qu'un bilan annuel avec un représentant d'un centre de référence, une rencontre annuelle avec le psychiatre ou le service envoyeur (cela peut être aussi un centre de référence) est importante pour maintenir une continuité, une histoire .<br>*avec la famille*nice dream<br><br>don't forget the parents !*niet verplichtend! wanneer een therapeutisch team hierom zou vragen, is het wenselijk dat dit inderdaad kán gebeuren door het referentiecentrum autisme<br>*Avant de pouvoir désigner un expert en autisme, il faudrait d'abord s'entendre sur ce que cela veut dire. Notre expérience en ce domaine n'est pas concluante. Le point de vue d'un centre de diagnostic et celui d'un lieu de vie sont trop différent pour que l'un puisse accompagner l'autre. Par contre il est tout à fait intéressant d'échanger sur nos points de vue différents et de travailler avec d'autres personnes d'autres institutions faisant un travail similaire. |

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| | | | | | | | | | | *I generally agree, but I do not think it should always be an expert from a reference centre. May depend on setting / case. Maybe it would also be useful to work with consultation teams (rather than specific individuals linked to specific teams)<br>* Not necessarily; it must be at the request of parents or team. Better state: an external expert should be available, and does not necessarily come from the reference centre for autism |
| **34** | Professionals should not work in isolation but share experiences with peers or be supervised. | 100% | 0% | 26 | 25 | 25 | | | 1 | *Selon mon expérience, cela se fait déjà, de manière et selon une intensité variable selon les secteurs et les services. De nombreuses équipes font appel à des supervisions d'équipe ou individuelles, se rencontrent autour de situations cliniques,...<br>*Totaly. |
| **35** | New professionals should be coached. | 100% | 0% | 26 | 25 | 25 | | | 1 | *by who?<br>*By who?<br>*Or to have someone they can count on.<br>*OK mais dans l'orientation qui correspond à leur choix et pas systématiquement selon une prise en charge cognitivo-comportementaliste.<br>*Il s'agit de donner aux services les moyens financiers et humains pour étoffer la formation, le soutien et l'accompagnement des nouveaux travailleurs |
| **36** | Awareness and support should be offered to professionals to prevent burn-out. | 96% | 4% | 26 | 24 | 23 | 1 | 1 | 1 | *Het meest belangrijke is dat er een goede organisatie van de hulpverlening is waar je voldoende tijd en middelen krijgt om je werk goed te doen. Waar er een evenwicht is tussen therapie geven en tijd om je onderzoeken te verbeteren en verslagen te maken, om teams bij te wonen. Waar er ook tijd is voor vorming. Dit in een werksituatie met een goede structuur. Waar je ook voldoende vakantie kan opnemen, gespreid over het jaar.<br>*Belangrijker is dat het werkdomein van de therapeuten |

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| | | | | | | | | | | | goed georganiseerd is. Dat er een evenwicht is % therapie-geven en % voorbereidingen, tijd om onderzoeken te verbeteren, tijd om verslagen en evaluaties te maken, tijd om te teamen en tijd voor overleg met externen,... Dat er geregeld vorming is waar er ook een ontspannend uurtje bij is. Ook de ondersteuning van een sterke en goede administratie is belangrijk. Er moet zoveel gebeuren. Wij doen ook één uur per week aan werkgroepen: bespreken welk materiaal aankopen, nieuwe ontwikkelingen,... .Dat ze gespreid over het jaar geregeld vakantie kunnen nemen.<br>*Cfr la question précédente<br>*Il serait également intéressant de faire une étude comparative du taux de burn-out et de l'ancienneté dans les institutions s'occupant d'autisme en fonction de l'orientation. |
| **Domain 2: Core features** | | | | | | | | | | | |
| ***Psychosocial interventions*** | | | | | | | | | | | |
| **Overall autistic behaviour** | | | | | | | | | | | |
| **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 | 86% | 14% | 26 | 21 | 18 | 3 | 4 | 1 | *Interventions should also take into account the stress levels of the child engaging in these interventions and especially any unwanted increase in stress<br>*Cette phrase me paraît extrêmement lourde et compliquée, la traduction française sur Google est totalement incompréhensible. Par contre, il me paraît évident que dans l'approche de ses enfants, il y a un réel apprentissage à faire au niveau des habiletés sociales et que celles-ci doivent être travaillées en parallèle avec les parents, les enseignants et les pairs, qu'elle passe d'abord par l'apprentissage de l'attention conjointe qui fait très souvent défaut aux enfants avec autisme et que de ce point de vue un apprentissage spécifique doit être |

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| 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. | | | | | | | | | réalisé est une évidence.<br>*Kinderen met autisme zouden zo vroeg mogelijk moeten gediagnosticeerd worden. Ideaal zou zijn dat ze toch zeker op 2-3 jarige leeftijd (vroeger mag ook) in een revalidatiecentrum terecht komen. Hierbij vind ik persoonlijk de inbreng van de logopedist heel belangrijk. De logopedist geeft de volgende therapie: algemene onwikkelingsstimulatie met accent op de gesproken taal. Ze richt zich op joint attention, imitatie en organisatievaardigheden, begrijpen van taal, uitbreiden van de productieve taal en dit allemaal gekaderd in het stimuleren van de basis communicatiefuncties, socio-emotionele vaardigheden en conversatievaardigheden. Je kan al deze aspecten niet opsplitsen. Je moet het kind in zijn totaliteit benaderen en je moet ook de verschillende doelstellingen simultaan remedieëren. Wanneer de kinderen overgaan naar het eerste leerjaar kan de logopediste het betreffende kind verder begeleiden mbt tot het schoolse leren: lezen en rekenen begeleiden, ev. dyslexie , ev. dyscalculie, begrijpend lezen (vaak een probleem). Als het kind op schools vlak voldoende mee is dan heeft hij ook meer energie over om zich te richten op de socio-communicatieve vaardigheden ed. Het eerste jaar bij de logopediste is best individuele therapie. De volgende jaren combinatie individueel en groepstherapie: beginnen met duo en vervolgens geleidelijk aan grotere groep. Ook hier is de logopedist de geknipte persoon: communicatie met de anderen,taalstimulering, zich houden aan de regels, ...Dus eigenlijk een kleuterklas in het klein simuleren. Daarnaast spelen de andere disciplines hun rol spelen. Kiné en ergo voor motorische problemen, zelfredzaamheid en voor schrijfmotoriek. Zij geven die |

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| | | | | | | | | | therapie natuurlijk vanuit hun kennis van autisme. Zij kunnen dit ook geven in kleine groepjes om zo ook een aantal socio-communicatieve vaardigheden te oefenen. Psychologen geven bij ons groepstherapieën vooral vanaf zes jaar en dit mbt het sociale. Belangrijk is hier de omgang met de medeleerlingen, spreken over aspecten van maatschappelijke integratie, pestproblemen bespreken, verder beurt leren afwachten, gespreksonderwerpen leren uitwerken, beleefdheidsregels verder stimuleren enzo. Op een bepaalde leeftijd hebben de kinderen met autisme ook nood aan psycho-educatie. Op welke leeftijd? En welke therapeut geeft dit? Psycholoog?<br>*Vroege opstart therapie (2-3 jaar) is belangrijk. Als het kind op peuter- of kleuterleeftijd in een revalidatiecentrum komt dan speelt de logopediste een belangrijke rol. Zij is de aangewezen persoon om algemene ontwikkelingsstimulatie te geven. Met accent op joint attention, imitatie, organisatievermogen, taalstimulering , communicatievaardigheden, socio-emotionele vaardigheden en conversatievaardigheden. Dit kan je niet opsplitsen maar moet in zijn totaliteit gegeven worden. Dit eerst in individuele therapie, later duo en nog later kleine groep (simulatie kleuterklasje). Het is ook belangrijk dat er een goed vertrouwensrelatie gelegd wordt. Verder natuurlijk ook kiné en ergo:motoriek, schrijfmotoriek, zelfredzaamheid,.. Vanaf 6 jaar kan de logopedist het schoolse opnemen + begrijpend lezen (vaak problemen) naast taal en communicatie. De psychologen geven dan groepstraining: sociale scripts, bespreken pestgedrag, beleefdheidsregels,.. Ook psycho-educatie aan het kind is dan belangrijk.<br>*This is a specific intervention of psychomotricians |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | *Cette question n'est pas claire, est même confuse car elle semble ne pas dire clairement ce qu'elle veut viser.<br>*la médiation doit pouvoir continuer avec les parents même pour les enfants en âge de scolarité<br>*dit kan in sommige gevallen zeer zinvol/gewenst zijn, maar niet voor iedereen<br>*La notion de "patterns de communication" induit une conception de la parole comme pur outil de communication, ce qui est un ravalement regrettable mais congruent avec la position des personnes autistes pour qui c'est bien la dimension qui excède la pure communication qui suscite l'angoisse et qu'ils tentent d'éliminer. Alors il est important de faire ce que cette recommandation 37 propose, de développer une possible communication avec tous les outils dont nous disposons mais c'est insuffisant. Il faut surtout d'établir un partenariat qui mette l'enfant en confiance et lui donne confiance et envie d'entrer en communication de manière vivante, personnelle et non seulement programmée.<br>*but also for school-aged children parent, carer or teacher mediation may be useful.<br>*Agree on most of it, also that it should be a trained professional; but this carries a risk of “overdoing” autism, which I witnessed in my clinical experience several times. Peer-mediation is important, but it looks like this is “the” solution and it isn’t |
| **38** | There is no evidence on the effect of individual psychoanalysis, therefore no recommendation can be provided. | 89% | 11% | 26 | 18 | 16 | 2 | 7 | 1 | *Cette affirmation me semble un peu excessive. Il n'y a pas de preuve non plus à ma connaissance qu'une approche individuelle, basée sur les théories psychanalytiques ne soit pas efficace. Il m'est arrivé d'entendre une conférence par des thérapeutes d'orientation analytique prenant en charge des enfants avec autisme, la démarche thérapeutique que j'ai |

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| | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | entendu me semblait intéressante, passant par des interactions concrètes et pouvant être porteur d'une amélioration. Même si ce n'est pas vers ce type d'intervention que j'aurais tendance à diriger un enfant autiste, faut-il pour autant empêcher ce type d'approche ? Je pense qu'il faut pour cette question tenir compte aussi des compétences cognitives des enfants ou adolescents, de leur capacité d'accéder ou non au symbolisme, je ne permettrai donc pas de trancher sur cette question, même si je crois réellement qu'une approche psychanalytique n'a pas vraiment de sens lorsqu'elle est réalisée auprès d'enfant n'ayant aucun langage et n'ayant de surcroît pas accès au symbolisme.<br>*Bien que n'étant pas de formation psychanalytique du tout, je constate que dans certaines structures que nous côtoyons au sein de la plateforme psychiatrique liégeoise, il existe des équipes qui fonctionnent en référence aux théories psychanalytiques et qui peuvent faire la preuve que plusieurs cas qu'ils suivent connaissent une réelle évolution en terme de communication sociale avec leur entourage. S'il n'existe pas de preuves scientifiques des effets de la psychanalyse, il n'existe pas non plus de preuve que cette approche ne permet pas de progression.<br><br>Je trouve personnellement délicat d'écrire qu'aucune recommandation ne peut être fournie...<br>*D'où sort cette affirmation péremptoire? Pourquoi à cet instant du questionnaire? Pourquoi n'est-il question que de la psychanalyse? Et les autres approches psychodynamiques telles que l'approche systémique, l'approche non directive,...? La psychanalyse n'a jamais prétendu être utile ou efficace pour tous les autistes. Mais |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | il y a suffisamment de témoignages d'analyse ou de psychothérapie d'enfants et d'adolescents indiquant le bénéfice qu'ils ont pu en retirer. Nous aurions pu attendre d'un organisme publique comme le KCE, qu'il prenne en compte toutes les approches.<br>*De quelle "psychanalyse" parle-t-on? De quel autisme parle-t-on? Nous faisons l'expérience qu'une prise en charge individuelle par un psychanalyste peut aider des enfants dit autistes (sur base du DSM-5) à sortir de l'autisme.<br><br>De plus, le manque de statistiques ne veut pas dire le manque de résultats.<br>*should be avoided/not recommended |
| **39** | There is no evidence on the effect of treatment in psychoanalytically oriented institutions, therefore no recommendation can be provided. | 88% | 12% | 26 | 17 | 15 | 2 | 8 | 1 | *should be avoided/not recommended<br>*CF RC 38<br>*Même réponse que pour RC 38<br>*Cette affirmation est choquante, voire injurieuse. A moins que le KCE ne soit absolument pas au courant de la réalité clinique de la prise en charge des autistes en Belgique! Si tel était le cas, cela montrerait un manque de rigueur; Si ce n'est pas le cas, il s'agirait d'un parti pris inacceptable. Le KCE sait-il que, par exemple, les centres de rééducation fonctionnelles, conventionnés avec l'Inami, et qui travaillent depuis plus de 40 ans avec notamment des enfants et adolescents autistes, sont tenus d'envoyer chaque année au médecin conseil de la mutuelle un rapport avec une évaluation suivant les outils Vineland, Harvey et Columbia? Est-ce notre faute si l'Inami ne s'est jamais donné les moyens pour réunir ces évaluations et en faire une étude?<br><br>L'affirmation du KCE indique une méconnaissance totale |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | du terrain. Le KCE aurait dû s'intéresser d'abord au travail gigantesque réalisé par des milliers de professionnels avant de s'attarder et de ne retenir que des rapports tendancieux venant de l'étranger.<br>*Il y a des évaluations nombreuses (Vineland, Harvey, Columbia) faites à la demande de l'INAMI, avec des résultats significatifs. Les centres de référence travaillent régulièrement avec des centres orientés par la psychanalyse et leurs évaluations sur base de tests randomisés (CARS) montrent également clairement les résultats obtenus. L'absence d'étude statistique ne signifie pas l'absence de résultats. |
| **40** | Regarding psychosocial interventions for restricted interests and rigid and repetitive behaviours, there is insufficient evidence that behavioural, cognitive or social-communication intervention or parent training has an effect on the core features of autism. Therefore no recommendation is provided for these types of interventions. | 68% | 32% | 27 | 22 | 15 | 7 | 5 | | *what is meant with psychosocialeintercventions?<br>*There's indeed not enough evidence for the effect on core features of autism, but what about interventions that aim at increasing quality of life (QoL) and 'using' restricted interests and repetitive behaviours to increase QoL?<br>*Dire qu'il n'y a pas d'évidence en ce qui concerne l'impact des interventions comportementales, cognitives ou de communication sociale sur les stéréotypies ou les intérêts restreints des enfants avec autisme, c'est peut-être vrai sur le plan strictement scientifique parce que les études menées à ce jour n'ont pas permis de le mettre en évidence, mais nous pouvons affirmer que nos interventions thérapeutiques, qui sont à la fois cognitives et comportementales permettent d'enrichir considérablement le champ d'intérêt des personnes avec autisme, qu'on voit dans de nombreuses situations les stéréotypies s'estomper de manière importante. Il est donc faux de dire que ces approches n'ont pas d'impact sur les traits caractéristiques de l'autisme et que par conséquent aucune recommandation ne peut être faite dans ce domaine. Par contre, je crois qu'il faudrait |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | |
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| | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | vraiment mettre en place des recherches, dans des structures thérapeutiques adéquates pour mesurer l'impact des interventions thérapeutiques et enfin pouvoir faire la preuve qu'elles sont efficaces à l'évidence.<br>*les interventions ont un impact sur le comportement des personnes avec autisme<br>*adequate intervention can bring progress<br>*het is zo dat deze beschreven interventies het "autisme" niet veranderen, maar ouderbegeleiding is wel zinvol om ouders met dit gedrag in hun gezinscontext te leren omgaan en de negatieve impact van dit gedrag op de gezinsrelaties tegen te gaan<br>*Cette recommandation suppose déjà comme allant de soi qu'il faut éliminer les comportement répétitifs et les intérêts particuliers. C'est déjà en soi une affirmation très discutable. Ces intérêts et ses comportements peuvent être la base de travail pour créer un partenariat et développer un champ de compétences. Ces comportements et intérêts font partie de la personnalité des personnes autistes, comme les intérêts particuliers et le style de chacun fait partie de lui. Le lui retirer c'est lui retirer une part de son être. Les autistes de haut niveau le disent eux-même.<br><br>Autre chose est de lui permettre d'évoluer, de s'enrichir, de se socialiser, etc. Je ne crois pas, en effet, que les techniques comportementales soient là les mieux à même de permettre ce développement.<br><br>On a essayé de retirer sa "machine à serrer" à Temple Grandin et heureusement, on n'a pas réussi. Cet intérêt particulier lui a permis de devenir ce qu'elle est devenue. Dans les centres de jour, il y a beaucoup de cas, sans |

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| | | Level of agreement | | Number of respondants | | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | | |
| | | | | | | | | | | | doute pas aussi heureux que celui de TG mais logiquement similaires.<br>*Studies are ongoing (CIPPA, coordination internationale entre psychothérapeutes psychanalystes s'occupant des personnes avec autisme)*Welke concrete invulling wordt hier gegeven aan de term psychosociale interventies?<br><br>*Even if ther is no scientific evidence, there is presomption of improvement<br>* This item is wrongly classified as a pharmacological intervention.”no recommendation” may be interpreted as “do nothing”, and this is absolutely not true. It is contradictory with other recommendations (e.g. N° 60) . Insufficient evidence does not mean that you have to do nothing |
| ***Pharmacological interventions*** | | | | | | | | | | | |
| **Overall autistic behaviour** | | | | | | | | | | | |
| **41** | Regarding pharmacological intervention for *overall autistic behaviour* there is insufficient evidence on the effect of SNRI’s and therefore no recommendation can be provided. | 100% | 0% | 28 | 22 | 22 | | 6 | | | |
| **Impaired reciprocal social communication and interaction** | | | | | | | | | | | |
| **42** | Regarding pharmacological intervention for *impaired reciprocal social communication and interaction* there is insufficient evidence on the effect of antioxydants and therefore no recommendation can be provided. | 100% | 0% | 26 | 17 | 17 | | 7 | 2 | | |
| **Restricted interests and rigid and repetitive behaviours** | | | | | | | | | | | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **43** | A) Regarding pharmacological interventions to target restricted interests and rigid and repetitive behaviours, there is insufficient evidence on the effect of antidepressants (especially SSRI's) and therefore no recommendation can be provided.<br>B) Pharmacological interventions involving antioxidants are not recommended to target restricted interests and rigid and repetitive behaviours. | 93% | 7% | 26 | 15 | 14 | 1 | 10 | 1 | *sometimes SSRI's can have an effect on rigid and repetitive behaviour<br>*sometimes SSRI's are used for rigid and repetitive behaviour, with effect<br>*N'étant pas médecin, je ne suis pas en mesure de répondre adéquatement à cette question, je peux juste dire qu'à ma connaissance il s'agit là d'une pratique qui n'existe pas chez nous, nous n'avons pas pour habitude d'utiliser des antidépresseurs pour réduire les intérêts restreints ou les gestes stéréotypés des enfants ou adolescents avec autisme. Je comprends qu'on n'introduise donc pas de recommandation à ce niveau.<br>*Cfr. RC 40.<br><br>Les comportement répétitifs et rigides ont une fonction qu'il faut prendre en compte. S'ils sont une manière de s'assurer une certaine immuabilité apaisante, il vaut mieux proposer des solutions alternatives qui lui conviennent que d'éradiquer la solution que l'enfant s'est trouvée. |
| ***Biomedical interventions*** | | | | | | | | | | |
| **Overall autistic behaviour** | | | | | | | | | | |
| **44** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target *overall autistic behaviour.* | 100% | 0% | 26 | 16 | 16 | | 9 | 1 | *Nous avons entendu parler comme tout le monde de cas particuliers d'enfants qui faisaient une vraie allergie au gluten qui ne parlaient pas du tout et qui ont commencé à développer le langage une fois qu'ils ont commencé un régime sans gluten. Mais aucun lien direct n'a pu être établi en terme de cause et d'effet.<br>*but, some individually targeted interventions can help ( for instance: glutenfree diet, see '' Reichelt '' )<br>*Dans l'état actuel des choses. |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **45** | Biomedical interventions involving other drugs such as antibiotics, antifungals, dextrometorphan, famotidine, amantadine, benzodiazepines and antihistamines are not recommended to target *overall autistic behaviour.* | 100% | 0% | 26 | 15 | 15 | | 10 | 1 | *Idem |
| **46** | Regarding biomedical intervention for *overall autistic behaviour,* there is insufficient evidence on the effect of complementary interventions (such as acupressure,acupuncture,electro-acupuncture and Qigong massage), nutritional interventions (with multivitamins and minerals, L-carnosine or L-carnitine, omega-3fatty acids) and sensory interventions (neurofeedback and auditory integration training). Therefore no recommendation can be provided for these interventions. | 100% | 0% | 26 | 19 | 19 | | 6 | 1 | *Nous savons que dans notre région, le Dr RAMAEKERS pratique des recherches sur les folates qui sont mis en cause dans le fonctionnement autistique. Mais ses travaux sont encore au stade des recherches et nous n'avons effectivement pas de résultats réellement concluants à ce jour pour recommander ce type d'approche. La médication qui est mise en place par ce neuropédiatre est souvent très onéreuse, il prescrit un ensemble de vitamines, de substances qu'il fait parfois venir de France ou d'ailleurs et qui coûtent très chères, avec des résultats qui à ce jour ne sont pas encore réellement probants. Donc, effectivement, je pense que la recherche dans ce domaine n'est pas encore assez loin pour qu'on ait des évidences, ce qui ne veut pas dire qu'il ne faille pas encourager la poursuite de ce type de travaux...<br>*Même si le massage, peut-être un moyen de prendre contact positivement et de manière apaisée avec l'enfant. En soi, bien entendu il ne traite pas l'autisme. Et mieux manger ne fait pas de tort, qu'on soit autiste ou pas. |
| **Impaired reciprocal social communication and interaction** | | | | | | | | | | |
| **47** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target | 100% | 0% | 26 | 16 | 16 | | 8 | 2 | *Toute réponse purement biomédicale me semble courte pour traiter un syndrome aussi complexe que l'autisme.<br><br>L'impact de l'alimentation et de l'environnement sont |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | *impaired reciprocal social communication and interaction.* | | | | | | | | | encore loin d'être correctement évalué, y compris pour les maladies somatiques. |
| **48** | Regarding biomedical intervention for *impaired reciprocal social communication and interaction,* there is insufficient evidence on the effect of complementary interventions (electro-acupuncture), nutritional interventions (multivitamins and minerals, L-carnosine or L-carnitine, omega-3 fatty acids) and sensory interventions (neurofeedback). Therefore no recommendation can be provided for these interventions. | 100% | 0% | 26 | 19 | 19 | | 6 | 1 | |
| **Restricted interests and rigid and repetitive behaviours** | | | | | | | | | | |
| **49** | Biomedical interventions involving hormone therapy (secretin), chelation, HBOT and gluten or casein free diets are not recommended to target *restricted interests and rigid and repetitive behaviours.* | 100% | 0% | 26 | 17 | 17 | | 8 | 1 | |
| **50** | Regarding biomedical intervention for *restricted interests and rigid and repetitive behaviours,* there is insufficient evidence on the effect of motor intervention (Kata excercise training) nutritional interventions (L-carnosine or L-carnitine) and sensory interventions (neurofeedback). Therefore no recommendation can be provided for these interventions | 100% | 0% | 26 | 16 | 16 | | 9 | 1 | |
| **Domain 3: Behaviour that challenges** | | | | | | | | | | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| ***Anticipating and preventing behaviour that challenges*** | | | | | | | | | | |
| **51** | Assess factors that may increase the risk of behaviour that challenges in routine assessment and care planning in children and young people with autism, including:<br>• impairments in communication that may result in difficulty understanding situations or in expressing needs and wishes<br>• coexisting physical disorders, such as pain or gastrointestinal disorders<br>• coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD<br>• the physical environment, such as lighting and noise levels<br>• the social environment, including home, school and leisure activities<br>• changes to routines or personal circumstances<br>• developmental change, including puberty<br>• exploitation or abuse by others<br>• inadvertent reinforcement of behaviour that challenges<br>• the absence of predictability and structure. | 91% | 9% | 25 | 23 | 21 | 2 | 2 | | *La formulation n'est pas satisfaisante. Cela fait partie d'un diagnostic clinique différentiel<br>*terms as 'such as' and 'including' are not necessary.<br>*Tous ces éléments sont à prendre en compte bien sûr, mais ils sont présentés ici comme une liste d'éléments distincts, de plus incomplète. "coexisting mental health problems such as anxiety or depression and other neurodevelopmental conditions such as ADHD" comme si cela n'avait rien à voir avec le fonctionnement autistique lui-même. C'est l'angoisse qui fait la recherche d'immuabilité. Faut-il rendre tout machiniquement immuable ou travailler avec l'enfant pour lui donner d'autres support que l'immuabilité, comme un appui relationnel par exemple qui lui permettrait de mieux supporter le changement?<br>*Cette liste présuppose déjà une théorie comportementale de l'autisme qui réduit la personne à ses comportements comme des troubles indépendants les uns des autres. Chacun de ces éléments est bien sûr intéressant à évaluer mais on ne peut considérer, que l'anxiété "coexiste" à l'autisme. De plus la dimension relationnelle et pulsionnelle me semble bien absente. |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **52** | Develop a care plan with the child or young person and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges, including:<br>• treatment, for example, for coexisting physical, mental health and behavioural problems<br>• support, for example, for families or carers<br>• necessary adjustments, for example, by increasing structure and minimising unpredictability. | 92% | 8% | 25 | 24 | 22 | 2 | 1 | | *Une telle formulation laisserait croire qu'il est possible d'élaborer un plan de soins de manière aussi rigide<br>*Même chose que pour la RC précédente.<br>*D'accord et pas d'accord. L'objectif du traitement est ici centré sur les comportements qui dérangent. Bien sûr, cela doit être traité mais ce qui se dégage d'une telle formulation est la réduction de la personne à ses comportements. |
| ***Assessment and initial intervention for behaviour that challenges*** | | | | | | | | | | |
| **53** | If a child or young person's behaviour becomes challenging, reassess factors identified in the care plan and assess for any new factors that could provoke the behaviour. | 96% | 4% | 25 | 24 | 23 | 1 | 1 | | *Notre approche est toujours à réévaluer dans une visée de qualité de vie pour la personne et non seulement en fonction du caractère dérangeant ou non de ses comportement. mais il est bien entendu que les comportements dérangeant peuvent témoigner d'un malaise mais aussi d'une évolution positive mais difficile à vivre pour la personne. C'est le cas en particulier quand elle se met à verbaliser. Prendre la parole, c'est se risquer à un changement et cela suscite de l'anxiété. |
| **54** | Offer the following to address factors that may trigger or maintain behaviour that challenges:<br>• treatment for physical disorders, or coexisting mental health and behavioural problems | 100% | 0% | 25 | 21 | 21 | | 4 | | *Adjustments: especially making things more predictable and clear, taking away anxiety that causes challenging behaviour<br>*Toutes ces remarques font partie intégrante d'un suivi psychothérapeutique digne de ce nom; Il ne faut pas négliger l'importance de la remise en question des intervenants eux-mêmes (professionnels ou parents) |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | • interventions aimed at changing the environment, such as:<br>• -providing advice to families and carers<br>• making adjustments or adaptations to the physical surroundings | | | | | | | | | quant à l'apparition de manifestions vives chez ces enfants et adolescents |
| **55** | If behaviour remains challenging despite attempts to address the underlying possible causes, consult senior colleagues and undertake a multidisciplinary review. | 100% | 0% | 25 | 23 | 23 | | 2 | | *senior or more specialised<br>*consult experts<br>*collegial consultation<br><br>Peer (intervisie |
| **56** | At the multidisciplinary review, take into account the following when choosing an intervention for behaviour that challenges:<br>• the nature, severity and impact of the behaviour<br>• the child or young person's physical and communication needs and capabilities<br>• the environment<br>• the support and training that families, carers or staff may need to implement the intervention effectively<br>• the preferences of the child or young person and the family or carers | 100% | 0% | 25 | 22 | 22 | | 2 | 1 | *Toevoegen: sensorische gevoeligheden en ontwikkelingsniveau van de persoon met autisme<br>*C'est ce que nous faisons depuis 40 ans en institution selon l'approche de psychothérapie institutionnelle à orientation psychanalytique!<br>**The frequency determines whether a particular behavior is a behaviorproblem or not.<br><br>Observation is important, and not only in the problem situation or the moment of the problem, but also when it goes well. |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | • the child or young person's experience of, and response to, previous interventions. | | | | | | | | | |
| ***Functional assessment*** | | | | | | | | | | |
| **57** | In the case of challenging behaviour a functional assessment should first be performed. | 91% | 9% | 25 | 23 | 21 | 2 | 1 | 1 | *D'autres évaluations que l'évaluation cognitivo-comportementaliste pevent être efficace<br>**if not predictable<br>*First an observation,<br><br>then an analyse,<br><br>then looking for possible causes.<br>*Une évaluation de la situation mais pas seulement "fonctionnelle". |
| **58** | The functional assessment should include a medical examination in order to exclude physical causes for pain. | 91% | 9% | 25 | 23 | 21 | 2 | 1 | 1 | *in children with severe intellectual disability, sometimes very difficult to assess physical causes of pain or difficult. When to decide to do further investigations (endoscopy, echo, blood, RX, ...?)<br>*Garder à l'esprit que la douleur physique peut être la cause du comportement difficile est PRIMORDIAL<br>*ICF can give a good sign.**Pas systématiquement. on ne peut pas aller chez le médecin à chaque crise. La visite chez le médecin est parfois trop insupportable. |
| **59** | The functional assessment should identify<br>• triggers for the behaviour,<br>• patterns of behaviour,<br>• the needs that the child or young person is attempting to meet by performing the behaviour, | 95% | 5% | 25 | 22 | 21 | 1 | 2 | 1 | *recognise the behavior and stop it before it will get worse have alternatives to stop the behavior before it will get worse<br>*c'est ce que nous faisons depuis 40 ans!<br>*The consequences of the behaviour for the child himself and the environment.<br>The time and resources that the person needs to get back to rest. |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | • the consequences of the behaviour. | | | | | | | | | *mais c'est loin d'être toujours possible de comprendre la fonction des passages à l'acte. |
| ***Psychosocial intervention*** | | | | | | | | | | |
| **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. | 90% | 10% | 25 | 20 | 18 | 2 | 4 | 1 | *Cette proposition est trop univoque! Une intervention psychosociale, comme vous dites, donc comportementale peut être une première ligne mais n'est sans doute pas la seule possible;<br>*J'ignore ce qu'il faut entendre par "intervention psychosociale". S'il s'agit d'un entraînement aux habiletés sociales, je pense que cela peut être pertinent, mais je crois plutôt qu'il faut toujours rechercher toujours plus avant les facteurs déclenchants, facilitant ou entretenant les comportements problèmes et que le plus souvent une bonne analyse fonctionnelle bien faite permet de mettre en place les interventions pertinentes qui vont agir soit sur les antécédents, soit sur les conséquents.<br>*Always combined with efforts to prevent and provide a calm, clear and structural environment. |
| **61** | There is insufficient evidence to recommend any specific type of psychosocial intervention. | 85% | 15% | 25 | 13 | 11 | 2 | 11 | 1 | *But creating a safe and predictable environment is probably first option<br>*Some psychosocial intervention can have positive effect commonly allowed<br>*Affirmation qui ne tient que dans le cadre de recherche de laboratoire!<br><br>Toutes ces recommandations ne visent qu'à arriver au résultats attendus dès le début de la recherche: favoriser Teacch et PECS..<br>*klinische praktijk toont echter wel dat:<br><br>voorspelbaarheid bieden<br><br>consequent opvoeden |

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| | | | | | | | | | | zeer duidelijk communiceren ev. met hulpmiddelen<br><br>…. de basis-aanpak is<br>*Comme je ne sais pas suffisamment ce qu'il faut entendre par "interventions psychosociales", je ne me prononcerai pas par rapport à cette question.*The mental and intellectual abilities play a role in whether or not recommend starting psychosocial interventions. |
| **62** | Psychosocial interventions for behaviour that challenges should include clearly identified target behaviour. | 81% | 19% | 25 | 21 | 17 | 4 | 3 | 1 | *Tout comportement fait partie d'un ensemble complexe. Cibler un comportement gênant c'est vouloir éradiquer et on sait que ce qu'on veut éradiquer, sans autre élaboration revient par un autre biais<br>*Je suppose qui si l'on fait un entraînement aux habiletés sociales, il est clair que les interventions doivent porter en priorité sur le comportement problème mais il est toutefois possible qu'il faille commencer par approcher les relations sociales de manière plus large avant d'aborder directement le comportement problème.<br>*Si on se centre sur un comportement en particulier, on peut simplement déplacer le problème. C'est le bien être et le développement de la personne qui doit être visé et non le comportement. |
| **63** | Psychosocial interventions for behaviour that challenges should include a focus on outcomes that are linked to quality of life. | 95% | 5% | 25 | 22 | 21 | 1 | 2 | 1 | *A quoi bon cet objectif? Toute intervention doit viser une meilleur qualité de vie, quelle que soit l'approche!<br>*pour la même raison que RC 62. |
| **64** | Psychosocial interventions for behaviour that challenges should include assessment and modification of environmental factors that may contribute to initiating or maintaining the behaviour. | 91% | 9% | 25 | 22 | 20 | 2 | 2 | 1 | *toevoegen op het einde "that challenges"<br>*And environmental factors include expectations and communication style of staff, care takers and parents<br>*that is very important!<br>*ce n'est pas la propriété des intevention spsychosociales<br>*When the child is capable to understand the |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | psychosocial interventions.<br>*Idem 62-63. |
| **65** | Psychosocial interventions for behaviour that challenges should include a clearly defined intervention strategy that takes into account the developmental level and coexisting problems of the child or young person. | 90% | 10% | 25 | 21 | 19 | 2 | 3 | 1 | *Over welk ontwikkelingsniveau spreekt men: cognitief of ook emotioneel?<br>*Cette question insinue qu'il pourrait y avoir des situations où on ne prenne pas en compte tous les aspects de la problématique présentée par l'enfant. Ce qui est une aberration<br>*Les hypothèses qui sous tendent la question sont pour moi irrecevables. Idem 62-63-64 |
| **66** | Psychosocial interventions for behaviour that challenges should include a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time). | 79% | 21% | 25 | 19 | 15 | 4 | 5 | 1 | *it is hard to tell in time how much time the young people or child needs to change his behavior<br>*How to define specific time necessary according to the specificity of each person.<br>*Une telle planification est une robotisation et ne tient pas compte de la complexité du psychisme<br>*steps, assessments !<br>*Intervention goals 'SMART(I)' specified<br>*Idem 62-63-64-65<br>*This carries a risk: some interventions need more time; so it must not be interpreted strictly |
| **67** | Psychosocial interventions for behaviour that challenges should include a systematic measure of the target behaviour taken before and after the intervention to ascertain whether the agreed outcomes are being met. | 74% | 26% | 25 | 19 | 14 | 5 | 5 | 1 | *systematic measure of the target behaviour: how?<br>*C'est une formulation coercitive, inadéquate pour la situation complexe que représente l'autiste<br>*dit moet niet steeds door meetschalen/vragenlijsten vastgelegd worden, dit kan ook aan de hand van een anamnese<br>*Small goals that are measurable<br>*Idem 62-63-64-65-66<br>*This is tricky, because sometimes there are significant microchanges , which may not become apparent when applying a standardized scale; so qualitative observations as are important as systematic measurements |

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| **68** | Psychosocial interventions for behaviour that challenges should be applied consistently in all areas of the child or young person's environment (for example, at home and at school). | 91% | 9% | 25 | 22 | 20 | 2 | 2 | 1 | *Plus que l'intervention technique, c'est davantage la manière dont cette intervention est effectuée qui est importante et qui a un effet; dans ce cas, il peut y avoir des interventions qui peuvent se faire à l'école, en institution ou en famille mais pas nécessairement partout et par tout le monde; une maman n'est pas une éducatrice ni une institutrice; la différence des fonctions et rôles est souvent importante à préserver pour faciliter le message adressé à l'enfant.<br><br>le qui fait quoi, quand et comment est une règle essentielle!<br>*bepaalde interventies kunnen thuis nodig zijn, maar minder relevant of onnodig op school<br>*Evidemment, sinon cela risque fort de n'aboutir à aucun résultat...!<br>*With specific attention to make transfers.<br>*il faut un minimum de cohérence et de lisibilité pour la personne autiste dans ses différents milieux de vie. mais la vie scolaire, institutionnelles et familiales ne peuvent fonctionner à l'identique. |
| **69** | Psychosocial interventions for behaviour that challenges should include agreement among parents, carers and professionals in all settings about how to implement the intervention. | 95% | 5% | 25 | 22 | 21 | 1 | 2 | 1 | *Cette univocité, cette uniformisation est un leurre car elle voudrait annuler les différences interpersonnelles;<br>*With specific attention to motivate the person himself |
| ***Crisis intervention*** | | | | | | | | | | |
| **70** | Crisis intervention should aim at providing protection, not punishment**.** | 100% | 0% | 25 | 23 | 23 | | 1 | 1 | *And should be told that way. |
| **71** | The use of isolation chambers should be restricted to exceptional cases | 91% | 9% | 25 | 22 | 20 | 2 | 2 | 1 | *And in dialoge with the young people why the isolation is used. |

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| | where all other approaches have failed and the person and the environment need protection. | | | | | | | | | *Je suis convaincu qu'une chambre d'isolement n'est pas nécessaire ni souhaitable pour les enfants et adolescents; c'est mon travail en institution (service K) depuis 40 ans qui me permet de dire cela. Nous n'avons jamais eu de chambre d'isolement (enfermement, fermeture à clef) alors que nous avons accueillis de nombreux autistes avec des manifestations d'angoisse extrêmement importantes<br>*Liever geen isolatiekamer.<br><br>Wel een omgeving waarvan men uit ervaring weet dat die de persoon in kwestie tot rust kan brengen. En dat kan afhankelijk van persoon tot persoon van alles betekenen: de natuur,een prikkelarme ruimte, maar ook een ruimte waar materiaal is of mensen zijn die de persoon een veilig gevoel geven, enz. Voor elke persoon zou beschreven kunnen worden welke omstandigheden er nodig zijn om de persoon in kwestie (opnieuw) een veilig gevoel te geven. |
| **72** | The use of isolation chambers should respect legal regulations and framework. | 96% | 4% | 25 | 24 | 23 | 1 | | 1 | *Pour les enfants et les adolescents, le recours à la chambre d'isolement est signe d'incompétence professionnelle ou de non engagement professionnel<br>*Zie RC71<br><br>Er moet "wettelijk" vastgelegd worden dat het op voorhand geregeld wordt dat, indien nodig, de juiste omstandigheden voor handen zijn.<br><br>En dat escalerend gedrag ten alle tijden preventief bestreden moet worden door een kwaliteitsvol bestaan. |
| **73** | The use of physical restraint should be restricted to exceptional cases where all other approaches have failed and | 91% | 9% | 25 | 23 | 21 | 2 | 1 | 1 | *But who decides that the person needs protection??<br>*Not in all cases. It can be used as prevention.<br>*Idem zoals RC 72 en 73 |

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| | the person and the environment need protection. | | | | | | | | | * Dergelijke "behandelingen" zorgen vandaag al te vaak voor getraumatiseerde mensen met autisme. |
| **74** | It is recommended not to use packing (wrapping in cold, wet towels). | 95% | 5% | 25 | 19 | 18 | 1 | 4 | 2 | Le packing peut être considéré comme un mode d'intervention agressif envers l'enfant. Son efficacité n'est pas démontrée scientifiquement. Son utilisation pose donc des problèmes éthiques majeurs.<br>*Unless that is what the child or young people have discussed before and is effective and is experienced as a punishement<br>*Quoique cette technique est controversée sans aucune nuance par certains, le recours au packing (qui se fait avec un accompagnement très important, peut s'avérer favorable pour répondre à des enfants ou des adolescents qui s'automutilent de manière incoercible. Il s'agit d'une technique à ne pas banaliser ni à diaboliser!<br>*should be forbidden !<br>*Aangeraden lijkt me wat te zwak.<br><br>Absoluut verboden klinkt beter. |
| ***Pharmacological interventions*** | | | | | | | | | | |
| **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. | 94% | 6% | 25 | 16 | 15 | 1 | 8 | 1 | *Une médication ne doit pas être prévue que s'il y a insuffisance des interventions. Une médication peut être conjointe à d'autres interventions, dans certains cas;<br><br>Il y a un paradoxe: L'autisme n'est plus repris dans un cadre psychiatrique mais considéré comme un handicap mais on a recours à des "antipsychotiques". pas très cohérent!<br>*seulement en cas d'urgence ou en accompagnement d'une intervention psychosociale*should be exceptionnal or complementary |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **76** | Prior to prescribing antipsychotic medication it is recommended to offer a full medical assessment including laboratory and/or functional tests upon indication. | 77% | 23% | 25 | 22 | 17 | 5 | 2 | 1 | *functional tests: which???<br>*mind paradoxal effects<br>*Je pense que ce type d'investigation médicale doit avoir été fait avant d'entreprendre une "intervention psychosociale". Mais si vraiment des difficultés particulières surviennent lors de la mise en place d'une intervention de ce type qui font penser qu'il pourrait exister un dysfonctionnement médical il va de soi que ce type d'investigation doit alors impérativement être pratiquée.<br>*A full medical assessment seems not always necessary<br>*il me semble que les compétences cliniques des médecins, avec l'aide des intervenants du quotidien peuvent suffire, avec information et accord préalable des parents. |
| **77** | Antipsychotic medication should be prescribed and monitored by a child psychiatrist, a neuropediatrician or an experienced pediatrician or neurologist. | 86% | 14% | 25 | 22 | 19 | 3 | 2 | 1 | *Only by a child psychiatrist<br>* ce doit être une obligation<br>*Translate and distribute : " Pharmautism"<br><br>( SPAIN, Dr FUENTES )*een kinderarts of neuroloog is onvoldoende bij machte om in te schatten of alle psychosociale interventiemogelijkheden uitgeput zijn, dit is de kerncompetentie van een kinder- en jeugdpsychiater<br>* It can be prescribed by the general practitioner in agreement with a child psychiatrist or neurologist |
| **78** | It is recommended that the prescriber identifies the target behaviour. | 81% | 19% | 25 | 21 | 17 | 4 | 3 | 1 | *Une telle formulation laisserait entendre que ce ne serait pas toujours le cas; cela paraît pourtant évident une prescription doit répondre à une hypothèse thérapeutique<br>*Ce n'est une fois de plus pas un comportement précis qui est visé mais la possibilité pour l'enfant ou le jeune de poursuivre positivement son évolution. Si l'angoisse l'envahit, si les passages à l'acte rendent la collaboration impossible. |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **79** | It is recommended that the prescriber decides on an appropriate measure to monitor effectiveness, including frequency and severity of the behaviour and a measure of global impact. | 95% | 5% | 25 | 20 | 19 | 1 | 4 | 1 | *même réponse que 78<br>*with the parents<br>*Avec la même réserve que pour RC78. |
| **80** | It is recommended that the prescriber reviews the effectiveness and any side effects of the medication after 3–4 weeks and regularly thereafter. | 95% | 5% | 25 | 21 | 20 | 1 | 3 | 1 | *by a face to face visit or also possible by mail of phone contact?<br>*Même réponse que 78. Un suivi des effets d'une prescription va de soi. Un tel rappel est-il nécessaire? |
| **81** | It is recommended that the prescriber stops treatment if there is no indication of a clinically important response at 6 weeks. | 87% | 13% | 25 | 15 | 13 | 2 | 9 | 1 | D'accord sur le principe, mais pas d'avis sur la durée (+ ou - que 6 semaines).<br>*c'est un minimum<br>*why 6 weeks ?*het effect van medicatie laat vaak enkele weken op zich wachten; soms dient de dosering aangepast te worden; het effect van een dosisverhoging laat ook soms enkele weken op zich wachten<br>*C'est au médecin d'en décider. |
| **82** | The prescription of antipsychotic medication should start at a low dose and should be maintained at the minimal effective dose. | 100% | 0% | 25 | 16 | 16 | | 8 | 1 | *C'est au médecin d'en décider |
| **83** | It is recommended not to allow caretakers or parents increase the dose 'as needed'**.** | 95% | 5% | 25 | 21 | 20 | 1 | 3 | 1 | |
| **84** | The choice of antipsychotic medication should take into account side effects, acquisition costs, the child or young person's preference (or that of their parent or carer where appropriate) and response to previous treatment with an antipsychotic. | 95% | 5% | 25 | 21 | 20 | 1 | 3 | 1 | *idem réponse 78 |

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| **85** | When a patient is transferred to primary care clear instructions should be provided regarding all aspects of the prescription but the responsibility is not transferred. | 100% | 0% | 25 | 15 | 15 | | 9 | 1 | Doutes concernant "the responsibility is not transferred" |
| **86** | The medical expert (child psychiatrist, specialist) should remain in charge of pharmacological treatment and see the patient at least once a year. | 95% | 5% | 25 | 22 | 21 | 1 | 2 | 1 | *Or even twice a year*Even two or three times a year *c'est minimaliste*at least, and review necessity of drug *more than once a year.At least twice a year. |
| **87** | Pharmacological treatment should be explained to the parents in a comprehensible way, if needed with written information on the therapeutic plan. | 100% | 0% | 25 | 24 | 24 | | | 1 | *Het is ook belangrijk om een duidelijke uitleg aan scholen te geven. |
| **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, risperdone and aripiprazole. | 75% | 25% | 25 | 8 | 6 | 2 | 16 | 1 | *D'expérience, le risperdal n'est pas particulièrement ni toujours efficace. le dipiperon est souvent efficace; *See: " Pharmautism " guide *N'étant pas médecin, je ne me sens pas apte à répondre à cette question, la seule chose que je puisse dire c'est que plusieurs des enfants que nous suivons reçoivent une prescription de Risperdal qui semble leur être bénéfique et elle a toujours été arrêtée lorsqu'elle ne donne pas de résultat probants. *Should mention at what age it is possible to start aripiprazole * This is too restrictive |
| ***Biomedical interventions*** | | | | | | | | | | |
| **89** | It is recommended to inform parents that currently trials involving massage, multivitamin and mineral supplement, electro-acupuncture, hormone treatment (secretin), medical procedures (HBOT and DMSA), | 89% | 11% | 25 | 19 | 17 | 2 | 5 | 1 | ... pour autant que cette affirmation soit vraie, bien entendu. *always inform about this topic or only when parents have questions about those interventions??? *Une information est nécessaire mais ce qui est prétendument validé par l'EMB est sujet aussi à caution! |

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| | nutritional and sensory interventions have not demonstrated efficacy against challenging behaviour in autism. | | | | | | | | | *Je suis d'accord avec cette affirmation, toutefois, on sait très bien que les parents confrontés à une détresse importante devant l'état de leur enfant sont parfois prêts à tout tenter pour que leur enfant aille mieux et il n'est pas rare que ces cas là, plus encore que dans d'autre, comme le disait Paul OSTERRIETH, "Tout conseil du PSY n'est autre qu'un effet oratoire inutile"<br>*Les parents peuvent s'informer par eux-même ou demander des informations. Mais il me semble contre-productif de les noyer sous une foule d'informations sur toutes les expérimentations non encore validées. |
| **90** | It is recommended to warn parents against unnecessary spending for alternative treatments that have not shown efficacy. | 90% | 10% | 25 | 21 | 19 | 2 | 3 | 1 | *Une information complète et nuancée est importante<br>*Toutefois, d'expérience, je serai tenté de répondre de la même manière que pour la RC 89<br>*Ils peuvent en parler au professionnels, leur demander leur avis et ceux-ci leur répondre. mais en prendre l'initiative serait en faire la publicité. |
| **Domain 4: Associated features of autism and coexisting conditions** | | | | | | | | | | |
| ***Impairments in adaptive behaviour*** | | | | | | | | | | |
| **91** | Based on an evidence based approach, there is insufficient scientific evidence for behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairment in adaptive behaviour. Therefore no recommendation can be provided. | 41% | 59% | 25 | 17 | 7 | 10 | 7 | 1 | *Some interventions have shown preliminary evidence...when will this evidence be sufficient??<br>*All recommendations shouldn't depend only on sufficient scientific evidence.<br>*Wanneer men logopedische therapie geeft ifv het verbeteren van de algemene taalontwikkeling en het remedieëren van de socio-communicatieve vaardigheden. Dan begrijpt het kind meer en kan het zich beter uitdrukken. Hierdoor kunnen gedragsproblemen verminderen.<br>*on the contrary<br>*met deze bemerking dat ouders wel kunnen geholpen worden om met deze specifieke beperking om te gaan |

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| | | | | | | | | | *Ce n'est pas après 40 ans de pratique de la thérapie cognitive et comportementale auprès d'enfants avec autisme que je vais laisser dire que nos interventions ne permettent pas une amélioration des comportements adaptatifs. Certes, les enfants et adolescents que nous avons suivis conservent peut-être ou même sûrement des caractéristiques autistiques, avec une certaine "étrangeté", une communication particulière, mais cela ne veut pas dire pour autant qu'il n'y a pas eu d'intervention efficace sur l'adaptation des comportements. Beaucoup sont capables de s'adapter aux milieux, même si certains restent "différents", ils sont certainement capables d'adaptation, alors non, je ne suis pas d'accord avec cette affirmation.<br>*Le choix thérapeutique doit être laissé au patient et à ses parents dans le cas des enfants. Il n'y a à ce jour aucune méthode recommandable à 100%. Pour des raisons éthiques, il faut privilégier celles qui respectent les choix des personnes concernées (et des parents) et mettent l'accent sur la qualité de vie, y compris l'intégration sociale.<br>*Parent-mediated early intervention for young children with autism spectrum disorders (ASD).<br><br>Oono, Inalegwu P. Honey, Emma J. McConachie, Helen.<br><br>Cochrane Database of Systematic Reviews. 10, 2013<br>Authors' conclusions<br>The review finds some evidence for the effectiveness of parent-mediated interventions, most particularly in proximal indicators within parent-child interaction, but also in more distal indicators of child language comprehension |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | and reduction in autism severity<br>* Even if ther is no scientific evidence, there is presomption of improvement<br>* Absence of evidence does not mean evidence of absence. This must be formulated more prudently. There are indications that these might be effective, but the problem is rather the methodology of scientific research. Don't blame the methods for lack of adapted research methodology |
| **92** | Based on expert consensus the GDG provided a recommendation to use PECS for children with autism and impairment in adaptive behaviour . | 60% | 40% | 25 | 20 | 12 | 8 | 4 | 1 | Le PECS n'est pas seulement utile pour les enfants, mais aussi (et peut-être surtout) pour les parents qui ont ainsi un moyen de communiquer avec leur enfant.<br>*Not for children who don't understand PECS pictures (at representation level). PECS can maybe recommended for 'some' children, those 'better' abilities*recommander particulièrement le PECS est un a priori, même si le PECS peut avoir des aspects très intéressants; La manière est aussi si pas plus importante que l'outil!<br>*Akkoord indien het kind, de ouders en de school dit steunen. Ze hebben misschien extra uitleg nodig over het hoe en waarom + meedelen dat dit een tussenstap is , dus tijdelijk. Daarom geregeld oudercontacten ed nodig.<br>*personalised communication system<br><br>Expert consensus vs. evidence based approach<br>*Dans l'approche thérapeutique que nous développons dans notre structure, nous avons rencontré des enfants qui malgré un retard intellectuel évident et d'importantes difficulté langagières au début de leur prise en charge sont parvenus à acquérir une communication langagière sans passer par le PECS. Donc nous sommes partisans d'utiliser le PECS lorsqu'effectivement notre approche thérapeutique ne donne pas les résultats escomptés et |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | que nous ne parvenons absolument pas à développer la communication entre l'enfant et son entourage. Mais tous les enfants avec autisme ne doivent pas forcément passer par le PECS. Certains en ont absolument besoin mais pas tous. Il y a tellement d'autismes différents qu'on ne peut pas imposer la même démarche ou approche de la communication à tous les enfants.<br>*L'usage d'images, de signes, de repères visuels a effectivement montré son efficacité pour aider les autistes à mieux ses repérer et communiquer avec leur entourage. il ne doit pas pour autant être systématisé de manière autoritaire mais proposé de manière ludique et dans le cadre d'un partenariat de confiance.<br>*I do agree with augmentative communication in general, but not PECS specifically, as it does not necessarily take the person's level of sense-making into account. See e.g. Noens & van Berckelaer-Onnes (2004) Making sense in a fragmentary world. Communication in people with autism and learning disability. Autism, 8, 197-218.<br>* Disagree: for some children PECS might help, but not for all, and not systematically |
| **93** | Pharmacological interventions are not recommended to treat isolated impairment in adaptive behaviour in children with autism. | 94% | 6% | 25 | 17 | 16 | 1 | 7 | 1 | *je ne comprends pas la question |
| **94** | Biomedical interventions including complementary interventions (e.g. acupuncture), hormone intervention (e.g. secretin), medical procedures (chelation or HBOT) and nutritional interventions (omega-3 fatty acids, gluten-free or casein-free diet) are not recommended to treat impairment in | 94% | 6% | 25 | 16 | 15 | 1 | 8 | 1 | *Là encore, je ne pense pas qu'on puisse empêcher les parents de tenter tout ce qui est possible pour faire progresser leur enfant, il est de notre devoir de les informer au mieux et de ne pas les bercer d'illusions, et donc, effectivement je pense qu'il ne faut pas faire de recommandation dans ce sens.<br>*C'est très bon pour tout le monde les omégas 3! Aussi |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | adaptive behaviour in children with autism. | | | | | | | | | pour les autistes mais pars pour traiter l'autisme comme tel. |
| **95** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve impairments in adaptive behaviour in children with autism. | 100% | 0% | 25 | 16 | 16 | | 8 | 1 | |
| ***Speech and language problems*** | | | | | | | | | | |
| **96** | 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 and should be initiated early on. | 82% | 18% | 25 | 22 | 18 | 4 | 1 | 2 | *But not only PECS!<br>*But communication can't be reduced to its functional dimension<br>*Tendancieux et univoque!<br>*Zeer belangrijk om vroege start therapie. Multidisciplinaire therapie met de hoofdbrok logo: zeker 2, liefst 3x per week. Relatie opbouwen + non-verbale en verbale basisvaardigheden worden aangebracht + simultaan de sociocommunicatieve vaardigheden. Wanneer het kind bv. twee jaar is en nog niet spreekt kunnen er ook enkele SMOG-gebaren (samen met gesproken taal) aangebracht worden om de communicatieve functies te bevorderen. Bv. SMOG voor 'nog'. PECS lijkt mij zeker zinvol om te overwegen als er onvoldoende voortuitgang is of om specifieke problemen op te lossen. Wel in overleg met ouders en kind.<br>*expert consensus vs. evidence based<br>*Pecs or other<br>*PECS is een van de methodes.<br><br>Alle andere die communicatie ondersteunen (en voldoende onderzocht) zijn OK.<br>*I do agree with augmentative communication generally, but not PECS specifically. See above. |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **97** | There is insufficient evidence to recommend arts-based interventions to address speech and language problems in children with autism. | 75% | 25% | 25 | 16 | 12 | 4 | 7 | 2 | *Il est des enfants et adolescents qui se structurent, s'expriment à partir et grâce au recours à une expression artistiques (peinture, musique)<br>*peut-être cela mériterait une étude*but it can help<br>*Il ne faut toutefois pas négliger le fait que certains enfants peuvent être sensibles à ce type d'approche et développer des compétences langagière en rapport avec leurs productions artistiques, mais il s'agit le plus souvent d'un outil s'inscrivant dans une démarche plus global et cela ne représente par conséquent pas un domaine nécessitant une recommandation particulière.<br>*arts based?<br>* Arts based intervention might work indirectly if it improves reciprocity, communication and adaptation; so one cannot simply state that is “not recommendable” |
| **98** | Based on expert consensus the GDG recommended to involve parents when addressing speech and language problems in children with autism. | 95% | 5% | 25 | 20 | 19 | 1 | 3 | 2 | *Je ne comprends pas la formulation anglaise*Thuisbegeleiding is een goed kanaal. Ook oudergesprekken met de logopedist zijn belangrijk. Wanneer de ouders , alleen of samen met de logopedist, een vragenlijst mbt taal en communicatie invullen. Dan geeft dit aan de ouders al een bewustwording van de tekorten. Zo gaan ze spontaan al op een paar zaken letten. Korte gesprekjes in de wachtzaal (als ze het kind ophalen) zijn ook zeer zinvol. Ook af en toe een observatiemoment van de therapie is zinvol. Zo zien de ouders hoe ze best met het kind omgaan. Je kan dan ook telkens één aandachtspunt in de kijker zetten waar ze op kunnen letten thuis. Belangrijk om de ouders niet te overstelpen met info. Beter geregeld zien met beperkte werkpunten.<br>*Ouder moeten in alle interventies betrokken worden als ervaringsdeskundigen.<br>*yes see also : |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | *Comments on Organisation and delivery of care* |
| | | | | | | | | | | | Parent-mediated early intervention for young children with autism spectrum disorders (ASD).<br><br>Oono, Inalegwu P. Honey, Emma J. McConachie, Helen.<br><br>Cochrane Database of Systematic Reviews. 10, 2013<br><br>Authors' conclusions<br><br>The review finds some evidence for the effectiveness of parent-mediated interventions, most particularly in proximal indicators within parent-child interaction, but also in more distal indicators of child language comprehension and reduction in autism severity |
| **99** | Based on expert consensus speech therapy is recommended in autistic children with identified speech and language problems. | 89% | 11% | 25 | 19 | 17 | 2 | 4 | 2 | | *problem is that speech therapy is not reimbursed for a child wit nl IQ, language problems AND the diagnosis of autism and also for a child with IQ < 86<br>*C'est une méthode parmi d'autres<br>*Ik denk dat de logopediste een zeer belangrijke rol heeft in de remedieëring van de spraak, taal, communicatieve functies en conversatievaardigheden. Deze aspecten moeten tegelijkertijd aangeboden worden, je kan dit niet opsplitsen. Ook de kernproblemen 'joint attention, imitatie en organisatie' worden geïntegreerd. Dit is noodzakelijk om de spraak- en taal opgang te brengen.<br>*expert consensus vs. evidence based<br>*Als de logopedist tenminste voldoende op de hoogte is van de specifieke autistische communicatieontwikkeling<br>*'speech and language therapy' would me more appropriate terminology. |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **100** | The indication for speech therapy should be determined independent of the child' s IQ and should be integrated in a multidisciplinary approach. | 81% | 19% | 25 | 21 | 17 | 4 | 2 | 2 | *sometimes parents choose for private speech therapy only and not in a multidisciplinairy appproach<br>*terminology see above |
| **101** | The goals of speech therapy should be clearly defined and the effect be evaluated regularly. | 91% | 9% | 25 | 22 | 20 | 2 | 1 | 2 | *terminology see above |
| **102** | Pharmacological interventions are not recommended to treat speech and language problems in children with autism. | 100% | 0% | 25 | 13 | 13 | | 9 | 3 | |
| **103** | Biomedical interventions, including complementary interventions (acupuncture), hormonal therapies (secretin), medical procedures (chelation or HBOT) and nutritional intervention (including omega-3 fatty acids, multivitamins or L-carnosine ) are not recommended to treat speech and language problems in children with autism. | 100% | 0% | 25 | 15 | 15 | | 8 | 2 | *Uiteraard moeten biologisch medische problemen gedetecteerd worden.<br><br>Een kind met autisme dat eetproblemen heeft kan ook com. problemen krijgen door allerlei tekorten. |
| **104** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve speech and language problems in children with autism. | 93% | 7% | 25 | 14 | 13 | 1 | 9 | 2 | *expert consensus vs. evidence based<br>*Je ne suis pas médecin, mais il me semble qu'il n'y a pas vraiment de raison pour que les problèmes de langage des enfants avec autisme progressent grâce à un traitement hormonale |
| **105** | It is recommended not to use the 'hands on' techniques of 'facilitated communication' for speech and language problems in children with autism. | 80% | 20% | 25 | 15 | 12 | 3 | 8 | 2 | *hands on?<br>* This is too radical negation; there are many ways of facilitated communication, good and bad; many ways to assist; research methodology failes |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **106** | It is recommended not to use auditory integration training for speech and language problems in children with autism. | 79% | 21% | 25 | 14 | 11 | 3 | 8 | 3 | *sauf pour des cas spécifiques*but should remain complementary |
| **107** | It is recommended not to use neurofeedback for speech and language problems in children with autism. | 100% | 0% | 25 | 12 | 12 | | 11 | 2 | |
| ***IQ, academic skills and learning*** | | | | | | | | | | |
| **108** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention to improve IQ, academic skills and learning in children with autism. | 50% | 50% | 25 | 16 | 8 | 8 | 6 | 3 | *at least, if you mean 'any particular' intervention<br>*there are sufficient scientific evidence for academic skills and Learning but not for improve IQ<br>*les progrès sont concomitants<br>*Si nous n'avons pas encore la preuve scientifique parce que nos résultats n'ont pas été publiés, nous pourrions tout de même mettre en avant le fait que notre intervention thérapeutique permet une amélioration parfois considérable du QI des enfants que nous suivons, malheureusement ce n'est pas le cas pour TOUS mais les évolutions annuelles des QI sont dans certains cas tout à fait manifestes. De même que bon nombre de nos enfants avec autisme font des progrès spectaculaires en terme d'apprentissage scolaire.<br>*although 'improving IQ' is debatable<br>* Even if ther is no scientific evidence, there is presomption of improvement<br>* Strongly disagree;improving academic skills and learning is something else than improving IQ; there is certainly not expert consensus on this |
| **109** | Based on expert consensus, the implementation of an educational intervention such as LEAP , an | 82% | 18% | 25 | 11 | 9 | 2 | 11 | 3 | *do noy know LEAP<br>*Pourquoi cette méthode et pas une autre?<br>*expert consensus vs. evidence based |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | alternative program for preschoolers and parents, should be considered and studied to improve IQ, academic skills and learning in children with autism. . | | | | | | | | | *Alors là, je suis content d'avoir participé à cette enquête parce que s'il existe effectivement une méthodologie particulière que je ne connais pas encore mais qui s'avère efficace et scientifiquement validée pour faire progresser le QI et les capacités d'apprentissage scolaire des enfants avec autisme, nous sommes preneurs et nous allons immédiatement nous mettre en recherche pour nous approprier cette démarche.<br>*nice to recommend although no centers in brussels and wallonia !<br>*although 'improving IQ' is debatable<br>* Why only LEAP? There are a number of other similar approaches which deserve further studying |
| **110** | Based on an evidence based approach, there is insufficient scientific evidence to recommend parent training to improve IQ, academic skills and learning in children with autism. However, expert consensus is to encourage parent involvement. | 65% | 35% | 25 | 17 | 11 | 6 | 6 | 2 | *Ouders moeten bij aanvang informatie krijgen over wat autisme is. Vervolgens zou thuisbegeleiding zeer zinvol zijn: informatieverstrekking, hoe omgaan met het kind en specifieke problemen bespreken. Het is denk ik zeer belangrijk dat het zich niet beperkt tot theoretische uitleg. Het observeren door ouders hoe anderen met het kind omgaan is zeer belangrijk. Daardoor gaan ze bepaalde gedragingen copieëren en beter met hun kind omgaan. Ook af en toe een observatie van de logopedische therapie<br><br>is belangrijk. Zo gaan de ouders automatisch bepaalde zaken veranderen.<br>*il est reconnu que l'action des professionnels et des parents se renforcent dans les apprentissages cognitifs<br>*there is evidence and parents have to be involved<br>*again, improving IQ is debatable<br>* Even if ther is no scientific evidence, there is presomption of improvement |

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| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **111** | Based on an evidence based approach, there is insufficient scientific evidence to recommend specific social-communication interventions to improve IQ, academic skills and learning in children with autism. | 46% | 54% | 25 | 13 | 6 | 7 | 9 | 3 | *Niet bewezen maar uit de praktijk blijkt dat er goede vooruitgang is op zowel talig vlak als schools leren.<br>*idem question 110<br>*see comment above<br>* It depends on what “social-communication interventions” are, how they are done, what is done, by whom, whether there are attempts of transfer, etc. |
| **112** | Pharmacological interventions are not recommended to improve IQ, academic skills and learning in children with autism. | 93% | 7% | 25 | 15 | 14 | 1 | 8 | 2 | *see comment above |
| **113** | Biomedical interventions, such as acupuncture, hormonal therapy (secretin), multivitamins and auditory integration training are not recommended to improve IQ, academic skills and learning in children with autism. | 94% | 6% | 25 | 18 | 17 | 1 | 5 | 2 | *see above |
| **114** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to improve IQ, academic skills and learning in children with autism. | 94% | 6% | 25 | 17 | 16 | 1 | 6 | 2 | *Qu'est-ce un consensus d'experts? c'est cela l'EMB? Aucune valeur un consensus d'experts triés en fonction d'une orientation particulière!<br>*see above |
| ***Sensory sensitivities*** | | | | | | | | | | |
| **115** | There is insufficient evidence to recommend animal-based interventions such as horseback riding to treat sensory sensitivities in children with autsim. | 56% | 44% | 25 | 18 | 10 | 8 | 5 | 2 | *l'équitation est un intermédiaire qui peut être TRES efficace auprès de certains enfants et adolescents autistes<br>*it helps some of them<br>*Qu'il n'y ait pas de preuves suffisantes je veux bien l'admettre mais il n'en reste pas moins vrai que dans certains cas, pour certains enfants, c'est une approche qui peut se révéler efficace pour améliorer la sensibilité |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | articulaire, le maintien postural et l'ajustement tonique aux stimulations procurées par le déplacement par un mouvement sinusoidal sur le dos d'un poney ou d'un cheval. Ce ne doit pas être recommandé comme étant facilitant à tous les coups, mais il ne faut pas l'exclure comme pouvant être facilitant de l'ouverture de l'enfant au contact et à la découverte de certaines sensibilités tactiles. Mais ce n'est pas une évidence.<br>*Als je dit behandelingen noemt ben ik het er mee eens. Uiteraard kan een kind er absoluut plezier van hebben en/of rustgevend zijn.<br>* To treat sensory sensitivities yes, but horseback riding may have other beneficial effects |
| **116** | There is insufficient evidence to recommend educational interventions to treat sensory sensitivities in children with autsim. | 64% | 36% | 25 | 14 | 9 | 5 | 9 | 2 | *Qu'entendez-vous par méthode éducative? Le martinet? La responsabilisation?...??<br>*A ma connaissance, certains enfants peuvent profiter favorablement d'une éducation au goût, à l'olfaction, à l'audition. Il peut s'agir d'interventions éducatives mais ce n'est pas une évidence et chez nous, cela s'inscrit dans une démarche plus globale.<br>* Strongly disagree; it depends on what kind of educational interventions; children with hypersensivity may learn to adapt to stimuli y natural sensitising |
| **117** | Pharmacological interventions are not recommended to treat sensory sensitivities in children with autism. | 92% | 8% | 25 | 13 | 12 | 1 | 10 | 2 | *sometimes antipsychotic medications is prescribed for a child with severe sensory hypersensitivity, when other appraoches are not sufficient |
| **118** | There is insufficient evidence to recommend biomedical interventions such as massage and auditory integration therapy | 80% | 20% | 25 | 15 | 12 | 3 | 8 | 2 | *Ce qui manque dans tout ce questionnaire est le manque d'argument. des affirmations péremptoires.<br>*On ne peut pas faire de recommandation pour l'utilisations de ces approches, il n'en reste pas moins qu'elles peuvent s'intégrer dans une démarche cognitivo comportementale plus globale où ce type de technique peut prendre tout son sens. |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **119** | Based on expert consensus the use of sensory integration therapy, and various massage techniques should be studied to evaluate the effect on sensory sensitivities in children with autism. | 90% | 10% | 25 | 20 | 18 | 2 | 3 | 2 | *Pourquoi pas? Le packing est aussi une approche visant les sensibilités sensorielles exacerbées!<br>*recommendations for research vs guidelines |
| **120** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to treat sensory sensitivities | 91% | 9% | 25 | 11 | 10 | 1 | 10 | 4 | *Un consensus n'est pas une valeur pour de telles recommandations formulées ainsi |
| ***Motor difficulties*** | | | | | | | | | | |
| **121** | There is insufficient evidence to recommend animal-based interventions such as horseback riding to treat motor difficulties in children with autsim. | 61% | 39% | 25 | 18 | 11 | 7 | 5 | 2 | *preuve ou pas preuves, d'expérience on sait que l'équitation peut être un intermédiaire TRES important pour les enfants autistes notamment.<br>*for some of them, it can help<br>*Là encore, je crois que dans une démarche globale de l'approche de la motricité de ces enfants, l'approche par l'équitation peut avoir une influence bénéfique sur la régulation du tonus, l'ajustement postural notamment et l' hippothérapie peut de ce point de vue être une approche extrêmement bénéfique. Malheureusement, cela n'a pas été mesuré scientifiquement.<br>*Opnieuw: niet als behandeling<br><br>Opnieuw: niet om autisme te "genezen".<br><br>Eventueel wel om motoriek te "verbeteren"<br><br>* Strongly disagree; it depends on what kind of educational interventions; children with hypersensivity may learn to adapt to stimuli y natural sensitising |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **122** | There is insufficient evidence to recommend behavioural interventions to treat motor difficulties in children with autsim. | 71% | 29% | 25 | 17 | 12 | 5 | 6 | 2 | *education can help<br>*Notre approche globale des enfants avec autisme comprend une approche cognitive et comportementale qui passe par la psychomotricité et nous pourrions montrer à l'évidence que notre approche fait progresser l'ensemble des enfants qui nous consultent. Après passage en psychomotricité, ils améliorent leur QDM mesuré par le test d'Osertesky et ils améliorent également leurs compétences en motricité de relation. |
| **123** | Based on expert consensus the implementation of an educational intervention such as LEAP, an alternative program for preschoolers and parents, should be considered and studied to improve motor difficulties in children with autism. | 85% | 15% | 25 | 13 | 11 | 2 | 10 | 2 | *'SUCH AS' LEAP, so not exclusively LEAP*do not know LEAP<br>*Tout le questionnaire est pipé! On voit très bien où vous voulez en venir dès la première question!<br>*expert consensus vs. evidence based recommendations for research vs guidelines<br><br>*Là encore, s'il existe un programme qui permet d'améliorer les compétences motrices des enfants que nous ne connaissons pas, nous sommes preneurs, mais je serai curieux de faire une étude pour savoir si cette approche améliore autant les enfants que celle que nous avons développé chez nous....!<br>*same comment before no center in brussels and wallonia<br>*but what are the effective components of LEAP --> remains to be studied<br>$ Not only LEAP but similar programmes |
| **124** | There is insufficient evidence to recommend parent training to treat motor difficulties in children with autism. | 63% | 38% | 25 | 16 | 10 | 6 | 7 | 2 | *La question n'est pas claire, n'est pas compréhensible. De quelle formation s'agit-il?<br>*la prise en charge commune professionnel-parent est une condition nécessaire<br>*in the contrary<br>*In de zin van: het is wél belangrijk (net zoals bij andere |

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| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | | | | | | | | | | kinderen) om motorische activiteiten te doen. Als ouder moet je dan wel weten hoe je eventuele weerstand (van je kind) tegen bewegen kunt verminderen of doen verdwijnen. |
| **125** | There is insufficient evidence to recommend social-communication interventions to treat motor difficulties in children with autism. | 81% | 19% | 25 | 16 | 13 | 3 | 7 | 2 | *Je ne comprends pas la question |
| **126** | Based on expert consensus, physical therapy should be considered in case of comorbid developmental coordination disorder, or other well specified motor problems that interfere with daily life, but only after clinical assessment and with regular re-assessments. | 89% | 11% | 25 | 18 | 16 | 2 | 5 | 2 | *Don't forget that developmental coordination disorders must also be considered as psychomotoric disorder<br>*expert consensus vs. evidence based recommendations for research vs guidelines<br>*De notre point de vue, il n'existe pas un enfant avec autisme qui n'ait pas besoin d'une aide psychomotrice.<br><br>Evidemment nous ne parlons pas de rééducation kynésithérapeutique mais de psychomotricité. |
| **127** | Pharmacological interventions are not recommended to treat motor difficulties in children with autism. | 100% | 0% | 25 | 12 | 12 | | 11 | 2 | |
| **128** | There is insufficient evidence for the use of biomedical interventions, such as hormonal therapy (secretin), nutritional interventions (omega-3 fatty acids, gluten-free or casein-free diet) to treat motor difficulties in children with autism. | 100% | 0% | 25 | 14 | 14 | | 9 | 2 | |
| **129** | Based on expert consensus it is recommended not to use hormonal therapy (secretin) to treat motor difficulties | 88% | 13% | 25 | 16 | 14 | 2 | 7 | 2 | *Pas besoin d'avis d'experts pour cela<br>*expert consensus vs. evidence based recommendations for research vs guidelines |
| ***Coexisting mental health problems*** | | | | | | | | | | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **130** | It is recommended to consider a cognitive-behavioural intervention to treat anxiety in children with autism who have the required verbal and cognitive ability to engage in CBT. | 89% | 11% | 25 | 18 | 16 | 2 | 5 | 2 | *CBT is ook toepasbaar bij andere problemen<br>*ACT would even be better<br>*IT depends, CBT is not the only possible treatment.<br>*Le traitement de l'anxiété n'est pas une question de comportement mais de vécu intime qu'il s'agit d'accompagner pour qu'il évolue vers un apaisement. |
| **131** | CBT should only be initiated after a thorough assessment of the child and with regular re-assessment performed. | 100% | 0% | 25 | 18 | 18 | | 5 | 2 | *Je ne connais pas CBT |
| **132** | It is recommended to adapt CBT to individual needs and the child's environment and to involve the parents in the treatment plan. | 95% | 5% | 25 | 20 | 19 | 1 | 3 | 2 | *Le traitement des besoins individuels et de l'environnement n'est pas qu'une question comportementale. La question est avant tout relationnelle. |
| **133** | It is recommended to consult the appropriate NICE recommendations for specific coexisiting mental health problems. | 93% | 7% | 25 | 15 | 14 | 1 | 7 | 3 | |
| **134** | Complementary interventions, such as omega-3 fatty acids, gluten-free, casein-free diet or chelation are not recommended to treat coexisting mental health problems in children with autism. | 93% | 7% | 25 | 14 | 13 | 1 | 9 | 2 | |
| ***Common medical and functional problems*** | | | | | | | | | | |
| **135** | It is recommended to first offer a detailed clinical assessment in children with autism and sleep problems. | 90% | 10% | 25 | 21 | 19 | 2 | 2 | 2 | *C'est une approche globale qu'il faut favoriser. |
| **136** | Based on expert consensus, In the case of persistent sleep problems, it is recommended to consult with a specialist with expertise in the | 84% | 16% | 25 | 19 | 16 | 3 | 4 | 2 | *Les problèmes de sommeil sont généralement dus à de l'inquiétude et de l'angoisse. Un bon accompagnement "humain" est très souvent suffisant<br>*expert consensus vs. evidence based |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | management of autism or paediatric sleep medicine for persistent sleep problems to consider pharmacological treatment (e.g. melatonine). | | | | | | | | | |
| **137** | Based on expert consensus feeding problems and eating behaviour deserve special attention in children with autism, and a multidisciplinary assessment should be performed to identify factors that matter. | 90% | 10% | 25 | 20 | 18 | 2 | 3 | 2 | *expert consensus vs. evidence based |
| **138** | Biomedical interventions, such as multivitamins, omega-3 fatty acids, secretin and immunoglobulines are not recommended to treat common medical and functional problems in children with autism. | 100% | 0% | 25 | 15 | 15 | | 8 | 2 | |
| ***Sexuality*** | | | | | | | | | | |
| **139** | Based on expert consensus affective and sexual development deserves special attention in children with autism. | 95% | 5% | 25 | 22 | 21 | 1 | 1 | 2 | *Comme pour tous les enfants<br>*like for other children<br>*expert consensus vs. evidence based |
| **140** | Based on expert consensus adapted sexual education should be proposed to adolescents with autism. | 91% | 9% | 25 | 22 | 20 | 2 | 1 | 2 | *Sexuele voorlichting kan best eerder starten<br>*and also to children, sex education does not have to wait until adolescence<br>*Une éducation sexuelle adaptée! Cela n'existe pas même pour les autistes pour qui la sexualité est sans doute une question particulièrement peu aisée à assimiler. Mais quant à prétendre à une éducation "adaptée" ...<br>*pourquoi " adapted "*why adapted ?**expert consensus vs. evidence based |
| **Domain 5: Improving the impact on the family** | | | | | | | | | | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **141** | Based on an evidence based approach, there is insufficient scientific evidence to recommend any behavioural intervention to improve the impact on the family of children with autism. | 95% | 5% | 25 | 22 | 21 | 1 | 1 | 2 | *C'est le contraire<br>*on the contrary ! |
| **142** | Based on expert consensus it is recommended to facilitate support for parents and to propose different support modalities. | 91% | 9% | 25 | 22 | 20 | 2 | 1 | 2 | *D'accord pour autant que ce soutien peut être référencé en fonction de la demande des parents. Tous n'attendent pas un soutien comportemental!<br>*expert consensus vs. evidence based |
| **143** | Based on expert consensus it is recommended that special attention be paid to signs of suffering and support seeking expressed by siblings and to propose different modalities to help. | 100% | 0% | 25 | 23 | 23 | | | 2 | *Idem question 142<br>*expert consensus vs. evidence based |
| **Domain 6: Adverse events** | | | | | | | | | | |
| **144** | It is recommended to balance drugs benefits and risks prior to prescribing psychotropic medication. | 100% | 0% | 25 | 21 | 21 | | 2 | 2 | |
| **145** | Parents should receive clear explanations on the expected benefit of the treatment and possible adverse events. | 96% | 4% | 25 | 23 | 22 | 1 | | 2 | *Cette question a déjà été posée précédemment |
| **146** | It should be verified that the explanation was understood. | 100% | 0% | 25 | 23 | 23 | | | 2 | *Any explanation to the parents should be understood. |
| **147** | Parents should be offered the possibility for continuous dialogue with the prescriber. | 96% | 4% | 25 | 23 | 22 | 1 | | 2 | *Cela va de soi! |
| **148** | Parents should be warned about the possibility of paradoxical reactions | 100% | 0% | 25 | 22 | 22 | | 1 | 2 | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | and know an action plan for seeking assistance. | | | | | | | | | |
| **GDG: Research recommendations** | | | | | | | | | | |
| **149** | The GDG recommends to promote community based research and to explore which research designs are best applicable to the population. | 100% | 0% | 25 | 18 | 18 | | 3 | 4 | *But the following list is too restrictive and doesn't include for example psychosocial and psychomotrician approaches.<br>* This is is too restrictive, and a biased selection; it should be more general, e.g. research interventions on “learning enhancement” programmes ddressed to the core features of ASD; psychosocial interventions, cognitive-mediational interventions, socio-emotional interventions, |
| **150** | Given a limited but encouraging amount of evidence, the GDG recommends to focus research interventions on the following domains: | | | | | | | | | *But the following list is too restrictive and doesn't include for example psychosocial and psychomotrician approaches. |
| | 1. the Picture Exchange Communication System (PECS) | 83% | 17% | 25 | 18 | 15 | 3 | 4 | 3 | |
| | 2. the Learning Experience and Alternative Program for Preschools and their Parents (LEAP) | 88% | 12% | 25 | 17 | 15 | 2 | 5 | 3 | |
| | 3. the Early Start Denver model (ESDM) | 94% | 6% | 25 | 16 | 15 | 1 | 6 | 3 | |
| | 4. the TEACCH model | 95% | 5% | 25 | 19 | 18 | 1 | 3 | 3 | |
| | 5. Speech and language therapy | 88% | 13% | 25 | 16 | 14 | 2 | 6 | 3 | |
| | 6. Psychopharmacological therapies for core features, challenging behaviour, associated features and coexisting conditions. | 94% | 6% | 25 | 17 | 16 | 1 | 5 | 3 | |
| **GDG: Research recommendations specific to the Belgian context** | | | | | | | | | | |

| AUTISM in CHILDREN and YOUNG PEOPLE: RECOMMENDATIONS | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| **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. | 100% | 0% | 25 | 23 | 23 | | | 2 | *expert consensus vs. evidence based |
| **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. | 91% | 9% | 25 | 22 | 20 | 2 | | 3 | *Maar opletten dat het geen administratieve belasting is. Ieder werkt het uit zoals het voor hem zinvol is gericht op de begeleiding van het kind. Eventueel een checklist opmaken zodat je kan nagaan of je niets over het hoofd ziet. Of een eenvoudig formulier met een aantal topics die al ingegeven zijn. Hierachter kan iedere discipline eventueel iets noteren. + welke doelstellingen dat je hebt voor de volgende zes maanden. |
| **153** | Care networks for children and young people with autism should be equally accessible to all. | 100% | 0% | 25 | 23 | 23 | | | 2 | *Cela existe déjà. Venez voir et informez-vous! |
| **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. | 95% | 5% | 25 | 22 | 21 | 1 | 1 | 2 | Mais la population cible devrait être clairement définie. Il faut éviter ques des patients se retrouvent dans ces formes très contraignantes de prise en charge par manque de disponibilité d'autres formes de traitement moins contraignantes.<br>*Les réseaux de soins existent déjà même s'ils sont insuffisants. Informez-vous sur la réalité de terrain<br>*doit rester l'exception*but should remain exceptional ! |
| **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 | 95% | 5% | 25 | 21 | 20 | 1 | | 4 | *L'accès à l'instruction est très important mais il faut pouvoir accepter aussi que certains enfants et adolescents sont en trop grande difficulté pour avoir accès à une scolarité. Cela de manière temporaire ou de manière partielle. L'école à l'hôpital (type 5) à cet égard est un outil très intéressant |

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|---|---|---|---|---|---|---|---|---|---|---|
| | | Level of agreement | | Number of respondants | | | | | | *Comments on Organisation and delivery of care* |
| | | Yes | No | Total | Used in % of agreement | Agree | Not agree | Unable to answer | No answer | |
| | their intellectual capacities. This includes also children with higher intellectual capacities than average. | | | | | | | | | |
| **156** | Professionals should be provided with adequate training and support. | 96% | 4% | 25 | 23 | 22 | 1 | | 2 | *La formation, bien sûr! Parmi les services s'inscrivant dans une approche psychodynamique, la formation est continue et intensive! |

# 8. REWORDING OF RECOMMENDATIONS AFTER STAKEHOLDER MEETING

**Table 38 – Recommendations that were reworded after the stakeholder meeting and validated by GDG**

| AUTISM IN CHILDREN AND YOUNG PEOPLE: RECOMMENDATIONS | | |
|---|---|---|
| | **Wording before stakeholder meeting** | **Wording after stakeholder meeting** |
| **Domain 1: Organisation and delivery of care** | | |
| **Organisation and delivery of care** | | |
| 21 | In professional communication, it is recommended to use the DSM-5 classification. | In professional communication, it is recommended to use the DSM-5 classification but DSM -IV -TR and ICD 10 are still valid during the transition period. |
| 22 | A go-between notebook or electronic tool is recommended to support communication between the professionals and the parents and child. | A go-between notebook or electronic tool is recommended to support communication between the professionals and the parents and child but electronic tools should be used for recording not for online communication. |
| 25 | The reference centres for autism have a specific role in supporting the networking. | The Reference Centres for Autism have a specific but not exclusive role in supporting the networking. Referrals should include all relevant collaborators. |
| 26 | Institutions, especially hospitals, should offer protocols to facilitate first contacts. | Institutions, especially hospitals, should provide their staff with a framework or flexible protocol to facilitate contacts when caring for children or adolescents with autism for any medical indication. |
| **Domain 3: Behaviour that challenges** | | |
| **Psychosocial intervention** | | |
| 62 | Psychosocial interventions for behaviour that challenges should include clearly identified target behaviour. | Psychosocial interventions for behaviour that challenges should include clearly identified target behaviour and attempt to assess and address the underlying cause of the behaviour. |
| 66 | Psychosocial interventions for behaviour that challenges should include a specified timescale to meet intervention goals (to promote modification of intervention strategies that do not lead to change within a specified time). | Psychosocial interventions for behaviour that challenges should include a specified timescale to meet intervention goals in order to promote modification of intervention strategies that do not lead to change within a specified time and to reassess the therapeutic strategy. |

| | | |
|---|---|---|
| **Domain 4: Associated features of autism and coexisting conditions** | | |
| **Impairments in adaptive behaviour** | | |
| 91 | Based on an evidence based approach, there is insufficient scientific evidence for behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairment in adaptive behaviour. Therefore no recommendation can be provided. | Based on an evidence based approach, there is insufficient scientific evidence for behavioural intervention, cognitive behavioural intervention, parent training or social-communication intervention for children with autism and impairment in adaptive behaviour. Therefore no recommendation can be provided. However, adaptive behaviour as an outcome (DSM- IV-TR) can be considered as core feature (recommendation 37). Problems with adaptive behaviour are part of what is described as Autism Spectrum Disorder in DSM-5. |
| 92 | Based on expert consensus the GDG provided a recommendation to use PECS for children with autism and impairment in adaptive behaviour . | Based on expert consensus the GDG provided a recommendation to use augmentative communication (such as PECS) for children with autism and impairment in adaptive behaviour. |
| **Speech and language problems** | | |
| 96 | 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 and should be initiated early on. | 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 augmentative communication, such as PECS and should be initiated early on. |
| Motor difficulties | | |
| 126 | Based on expert consensus, physical 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. | Based on expert consensus, psychomotor and occupational therapy should be considered in case of comorbid developmental coordination disorder or other well specified motor problems that interfere with daily life, but only after clinical assessment and with regular re-assessments. |
| **GDG: Research recommendations** | | |
| 150 | Given a limited but encouraging amount of evidence, the GDG recommends to focus research interventions on the following domains: | |
| | 1. the Picture Exchange Communication System (PECS) | 1. Augmentative communication such as Picture Exchange Communication System (PECS) |
| | 2. the Learning Experience and Alternative Program for Preschools and their Parents (LEAP) | 2. Learning Experience and Alternative Program for Preschools and their Parents (LEAP) |
| | 3 the Early Start Denver model (ESDM) | 3. Early Start Denver model (ESDM) |
| | 4.the TEACCH model | 4. TEACCH model |
| | 5.Speech and language therapy | |
| | 6. Psychopharmacological therapies for core features, challenging behaviour, associated features and coexistingconditions. | |