

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

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Casus 3

- ***Bram is een 13-jarige jongen met zwaar autisme. Er zijn vier kinderen thuis. Mama heeft inmiddels een nieuwe relatie. De biologische vader van Bram maakt het gezin het leven zuur. Hij is eveneens autistisch en mishandelt Bram als hij op bezoek gaat. Bram heeft het dan nog moeilijker wanneer hij terug komt. Hij gaat al op internaat, maar de WE en vakanties zijn zeer moeilijk. Ze vragen jou als huisarts wat er nog kan gebeuren? Gezinsondersteuning? Je denkt al aan de lange wachtlijsten. Of is misschien accupunctuur een oplossing. Ze hebben een artikel van het internet bij.***





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. BELGIUM

GENEVIÈVE VEEREMAN, KIRSTEN HOLDT HENNINGSSEN, MARIJKE EYSSSEN, 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

The need for a guideline

- **The Request to develop guidelines for GCP was introduced by**
 - **Parent organizations of children and adolescents with ASD**
 - **The INAMI/RIZIV**
 - **The Superior Health Council(HGR/CSS)**
 - **Professionals caring for persons with a double diagnosis**
 - **Publication of the report by HGR/CSS (up to 6 years of age)**
 - **Shift in treatment modalities**

Scope of the guideline

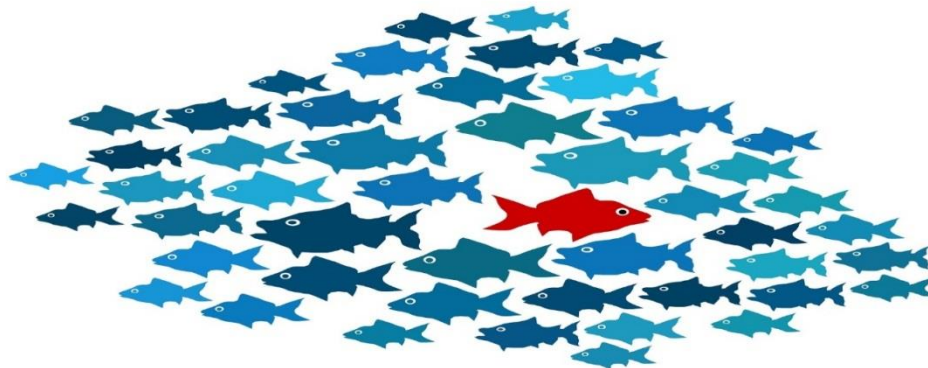
- **To provide recommendations based on current scientific evidence** and expert consensus
- Concerning good clinical practice (GCP) and improvement of the quality of health care
- **For children and adolescents (up to 18 years of age) with autism and their family.**
- **To deal with all the aspects of treatment and support**
- **To decrease the use of unnecessary or harmful interventions.**

Scope of the guideline

- **Not indicate an exclusive course of action or to serve as a standard of care.**
- **Not a substitute for a coherent clinical judgment or a proper diagnosis**
- **Interpretation of these recommendations in the context of the individual situation and a treatment tailor made to the individual child or youngster**
- **Deviations from the GCP should be fully documented**

Autism Spectrum Disorder (ASD)

- **Diagnosis according to DSM-5 criteria**
 - **persistent deficits in social communication and social interaction across multiple contexts**
 - **restricted, repetitive patterns of behaviour, interests or activities**
- **Comorbidities in 40 to 50 % e.g. intellectual disability**
- **Behaviour that challenges and associated features**
- **Approximately 70,000 cases in Belgium(all ages)**



'The world needs different
kinds of minds to work
together'



Temple Grandin



Methods

- **Scoping meeting (experts and stakeholders)**
- **Recent qualitative guidelines (Agree II)**
 - **NICE 2013 (GB)**
 - **HAS 2012 (Fr)**
- **Adapte methodology**
 - data from both guidelines summarized and discussed by GDG
 - consensus, never in contradiction with (scarce) evidence
 - 'KCE' recommendation formulated
- **Delphi method for voting to obtain >85% consensus**
- **Recommendations**
 - general: 148 – research: 2 – specific for Belgian context: 6
 - discussed and rephrased by stakeholders

ASD domains analysed

1. Experience of care and the **organisation** and delivery of care
2. Interventions aimed at **core features** of autism
3. Interventions aimed at **behaviour that challenges**
4. Intervention aimed at **associated features** of autism and co-existing conditions
5. Interventions aimed at improving the impact of the **family**
6. **Adverse events** associated with interventions

Positive recommendations on psychosocial interventions

- A** **Specific social-communication intervention for **core features****
- including play-based strategies with parents, carers and teachers
 - delivered by a trained professional
 - parent, carer or teacher mediation
 - peer mediation
- B** **Psychosocial intervention as a first-line treatment for **challenging behaviour****
- C** **Use augmentative communication techniques such as Picture Exchange Communication System (PECS) for impairment in **adaptive behaviour****
- D** **Speech and language problems: personalized project**
- functional objectives
 - may include PECS
 - early start
 - involve parents
 - independent of IQ
 - integrated in multidisciplinary approach
- E** **Academic skills, learning and motor difficulties: educational intervention such as Learning Experience and Alternative Program for Preschools and their Parents (LEAP)**
- F** **Developmental coordination disorder**
- psychomotor and occupational therapy
 - clinical (re) assessment
- G** **Anxiety: cognitive-behavioural treatment intervention (CBT)**

Positive recommendations on pharmacological interventions

- | | |
|----------|---|
| H | Behaviour that challenges : antipsychotic medication <ul style="list-style-type: none">• when psychosocial or other interventions are insufficient• could not be delivered because of the severity of the behaviour |
| I | Behaviour that challenges : comparable efficacy <ul style="list-style-type: none">• haloperidol• risperidone• aripiprazole |
| J | Persistent sleep problems <ul style="list-style-type: none">• consult with a specialist with expertise• consider pharmacological treatment (e.g. melatonin) |

Negative recommendations

K	Hormone therapy (secretin), immunoglobulins, chelation, HBOT and gluten- or casein- free diets are not recommended
L	Antibiotics, antifungals, dextrometorphan, famotidine, amantadine, benzodiazepines and antihistamines are not recommended
M	No recommendation b/o insufficient evidence: <ul style="list-style-type: none">• complementary interventions (acupressure, acupuncture, electro-acupuncture, hands on facilitated communication, Qigong massage)• nutritional interventions (multivitamins and minerals, L- carnosine or L- carnitine, omega-3 fatty acids)• sensory interventions (neurofeedback and auditory integration training)• motor intervention (Kata exercise training)
N	The use of isolation chambers and physical restraints should be restricted to exceptional cases where all other approaches have failed and the person and the environment need protection.
O	It is recommended not to use packing (wrapping in cold, wet towels).

Challenging behaviour

- Understanding of the meaning and causal factor of the behaviour
- Psychosocial, preventive and behavioural interventions
- The use of isolation chambers and physical restraints should be restricted to exceptional cases where all other approaches have failed and the person and the environment need protection.
- It is recommended not to use packing (wrapping in cold, wet towels).

GDG recommendations for research

- 149
- Promote **community based research**
 - Explore **research designs**

150 **Focus research on psychosocial interventions**

1. **Augmentative communication such as Picture Exchange Communication System (PECS)**

2. **Learning Experience and Alternative Program for Preschools and their Parents (LEAP)**

3. **Early Start Denver model (ESDM)**

4. **TEACCH model**

5. **Speech and language therapy**

6. **Psychopharmacological therapies** for core features, challenging behaviour, associated features and coexisting conditions

GDG recommendations specific to the Belgian context

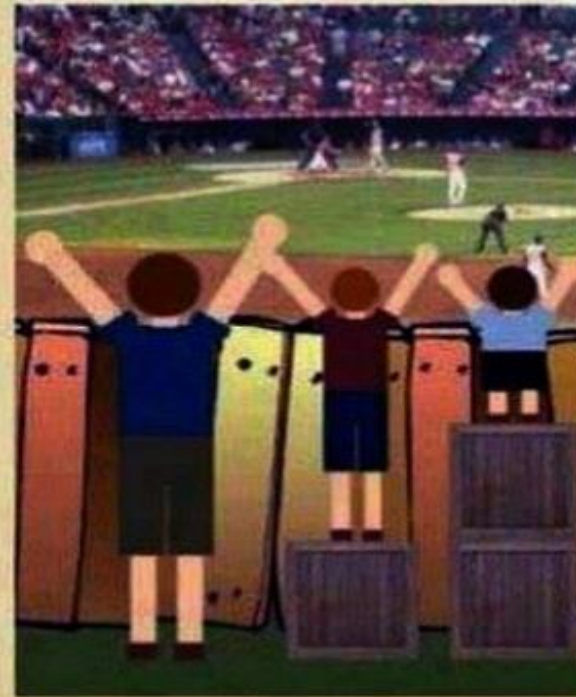


- ❖ Elaborate an **individual plan**.
- ❖ **Education** should be tailored to all, including higher IQ.
- ❖ **Professionals** need **adequate training and support**.
- ❖ **Home based care networks**, equally accessible to all.
- ❖ Provide **adapted residential care** for crisis.

Equality doesn't mean Justice



This is Equality



This is Justice

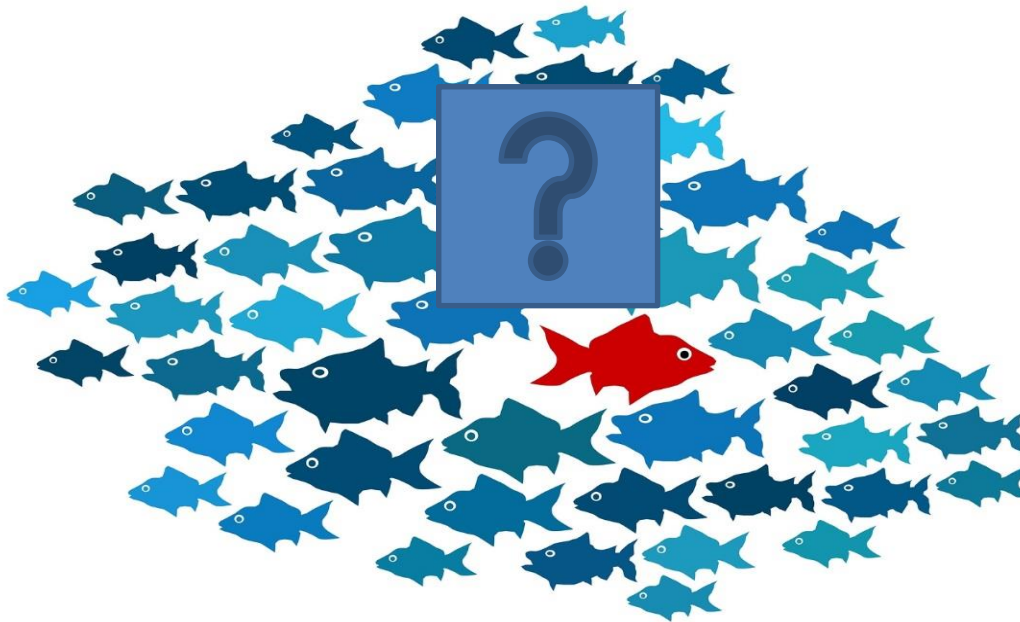


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Thank you for your attention



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