CONSENSUS FOR THE CHILD

The power of autism
AUTISM

TOWARDS A GLOBAL CONSENSUS

Philippe EVRARD
University of Paris Diderot
TOWARDS A GLOBAL CONSENSUS

- Recommendation for good practice
- Public Health and Funding
- Quality evaluations, certifications and accreditation
- Early detection and intervention
- Behavioral and cognitive methods
- Pathophysiology, genetic and epigenetic progresses
CONSENSUS FOR AUTISM

RECOMMENDATION

- FOR GOOD PRACTICE
- PERMANENTLY UPDATED
- WITHOUT CONFLICT OF INTEREST
METHODS FOR CONSENSUS IN PEDIATRICS

AS A BASIS FOR A NEW GOVERNANCE OF PUBLIC HEALTH AND CARE DELIVERY
The medical consensus processes: new tools
History of the consensus processes

- Iroquois Haudenosaunee (1142)
- Quaker model (17th century)
- Bureau Veritas
- Women’s liberation movement
- Ringi-sho (Japan) and Mass Gen Hosp (Boston): bottom to the top
- ISO (Intl Organization for Standardization)
- NIH, Consensus Development Program, Office of Medical Applications of Research OMAR, NIH, 1977
- NICE, U-K
- KCE, Belgium
- Haute Autorité de Santé, 2004
Consensus (Latin: feel together)

- **Definition** *(Merriam – Webster)*:
  - 1st: general agreement;
  - 2nd: group solidarity of belief or sentiment

- **Consensus decision making process**:
  - 1st: agreement of most participants;
  - 2nd: resolution or mitigation of minority objections
Consensus: dangers and bias

**Bias**
- Collective opinion, dictatorship of majority, politically correct
- Dominance
- Abilene paradox
- Time consuming

**Remedies**
- Financer’s declaration of objectives
- Appropriate selection of participants (dominant personalities !)
- Synthesis of the prexistant information
- Veto
- Definition of agreement degrees
Famous failures of the consensus process (when used without methodological tools)

- Neurological prognosis of preterm births
- 1970 – 1985
- More than 1,000 « consensus panels »
Abilene paradox

A group can unanimously agree on a course of action that no individual member of the group desires because no one individual is willing to go against the perceived will of the decision-making body.
Methods for consensus

- Delphi Method
- Nominal Group Technique
- Consensus Conferences
- RAND / UCLA
The Delphi process takes its name from the Delphic oracle’s skills of interpretation and foresight

<table>
<thead>
<tr>
<th></th>
<th>DELPHI</th>
<th>Nominal group</th>
<th>RAND / UCLA</th>
<th>Consensus panel</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Goals</strong></td>
<td>To obtain a final, convergent opinion</td>
<td>To reach a hierarchical order of priorities</td>
<td>Evaluation of the legitimate use of tools and treatments</td>
<td>Production of written recommendations</td>
</tr>
<tr>
<td><strong>Method</strong></td>
<td>• Questionnaire</td>
<td>• Two anomymous individual tours (during a meeting)</td>
<td>• Combination of the Delphi and Nominal Group Technique</td>
<td>* Combination of #1, #2, and #3 • Public debate • Consensus of the jury (in private)</td>
</tr>
<tr>
<td></td>
<td>• Individual anonymous answers</td>
<td>• Avoidance of dominance</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>• Feedback</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Pre-established rules</td>
<td></td>
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</tr>
</tbody>
</table>
The consensus decision-making process in itself: flowchart

- Not only the agreement of most participants
- But also the resolution or mitigation of minority objections
<table>
<thead>
<tr>
<th>Levels of evidence</th>
<th>Level of recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong>&lt;br&gt;• Robust comparative randomised trials&lt;br&gt;• Meta-analysis of randomized trials&lt;br&gt;• Decisional analysis based on robust studies</td>
<td>A&lt;br&gt;Fully proved</td>
</tr>
<tr>
<td><strong>2</strong>&lt;br&gt;• Weak comparative randomized trials&lt;br&gt;• Well runned non randomized studies&lt;br&gt;• Studies of cohorts</td>
<td>B&lt;br&gt;Scientific assumption</td>
</tr>
<tr>
<td><strong>3</strong>&lt;br&gt;• Studies of witness cases</td>
<td>C&lt;br&gt;Low level of proof</td>
</tr>
<tr>
<td><strong>4</strong>&lt;br&gt;• Comparative studies with bias&lt;br&gt;• Retrospective studies&lt;br&gt;• Series of cases</td>
<td>C&lt;br&gt;Low level</td>
</tr>
</tbody>
</table>
Medical consensus: *its bases and applications*

- Brainstorming: *preparation of consensus*
- Robust basic, translational, and clinical research: *basic conditions*
- State-of-the-art (or state-of-science): *two aspects: tool and/or conclusion of consensus*
- Solid meta-analysis if necessary (*high quality is rather rare*): *methodological component*
- Evidence – based knowledge: *preparation of consensus*
- Practical guidelines: *application of consensus*
Evidence – based practice
(Gordon Guyatt, 1980, McMaster)

<table>
<thead>
<tr>
<th>Bases</th>
<th>Limits</th>
</tr>
</thead>
<tbody>
<tr>
<td>From systematic reviews from of double-blind, placebo-controlled (at the top) to conventional wisdom (at the bottom)</td>
<td>Conflicts of interest</td>
</tr>
<tr>
<td>Meta-analyses</td>
<td>Dominance</td>
</tr>
<tr>
<td>Recognizes the individual factors (« best prediction » as debate continues)</td>
<td>Nonadherence, clinical inertia, therapeutic inertia</td>
</tr>
<tr>
<td>Ex cathedra by medical experts: least valid form of evidence and sometimes dangerous</td>
<td>Defective information</td>
</tr>
</tbody>
</table>
Evidence – based practice

- EBM fully recognizes multiple factors and individualized medicine

Clinical experience 
Research results 
Decision
Preferences of patient

*Individualized # Personnalized*
Consensus for Autism (ASD)

- French recommendations for good practice in autism (*Haute Autorité de Santé, HAS, 2012*)
- British recommendation (*National Institute Care Excellence, NICE, 2013*)
- Belgian recommendation (*Federal Center KCE, 2014*)
FRENCH RECOMMENDATION FOR GOOD PRACTICE IN AUTISM

HAUTE AUTORITÉ DE SANTÉ
Law of August 13, 2004:
• To keep national solidarity in Public Health through the Social Security system
  • To reinforce quality of care
  • For the benefit of patients

Methods:
• Consensus «formalisé» HAS
• Recommendations and priorities for good practices
Autism and autism spectrum disorders
Programs and interventions for children and adolescents

Pr Philippe EVRARD, président du groupe national de pilotage, HAS
Joëlle ANDRE – VERT, chef de projet HAS

Recommendations of good practices
Recommendations of good practices are

- key proposals
- methodically developed (consensus panels)
- to help practitioners and patients (users)
- to select the most appropriate care planning in a given clinical situation

At the level of the relationship between professionals and patients and not directly at the level of the public health policy
Comité d’organisation

Groupe de pilotage
  + Groupe élargi

Groupe de cotation

Groupe de pilotage

Consultation publique
  Groupe de lecture

Groupe de pilotage + groupe de cotation

Validation HAS - ANESM

Recommandation
  Texte validé et publié des recommandations

instances de validation

Note de cadrage

Argumentaire propositions

Propositions consensuelles

1ère version des recommandations

Cotation Commentaires

Version finalisée des recommandations

March 9, 2012
Main questions submitted to consensus

1. Which evaluations, how often, by which professionals?
2. How to use the evaluations?
3. Which intervention programs?
4. Practical planning and organization of medical (sanitary), medico-social and education resources?
Beyond the medical aspects

Child / adolescent

parents

school

medical

Medico-social
Specific aspects in France

- Universal health coverage (CMU and "national solidarity")
- Robust centralized planning
- Financial allocations by local authorities
- Very severe shortage in France (1/3)
Situation in France

- GNI: US $ 40,000 > 13% for health care delivery
- Autism: 1,4 billion €
- 1/3 of severe disabilities and autism are well treated

European comparisons
Funding of care for disabled children and adolescents

- Keys of success (f.i.: Belgium, Sweden, Switzerland, UK)
  - Multitrack
  - Partnerships
  - Transmission cables to support governmental budgets and decisions
  - Competition
  - Decentralized

- In the countries with similar health budgets (13% of GNI – PPP – intl $ above US $ 30,000), results for disabled persons are very different
Autism, HAS, January 2009 – March 2013

- 140 national and foreign experts
- 23 scientific and professional societies
- 7 governmental departments
- 1 national academy
- 202 institutions and associations
- 10 analysts, methodologists and research officers
- 800,000 euros
Hierarchy of recommendations

- A: Strong scientific evidence
- B: Scientific presumption
- C: Low level of evidence
- D: Agreement of experts
Good Practices, Autism, HAS

- The patient and his parents: active partners
- Periodic developmental evaluation
- Program based on the results of evaluation
- Early integrative and pluridisciplinary intervention
- Detailed recommendations for the use of medications
- Planning of coherence and continuity of interventions from the diagnosis to transition between adolescence and adult age
Among the interventions initiated before 4 years:

<table>
<thead>
<tr>
<th>Recommended</th>
<th>Level of recommendation</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABA and its variants</td>
<td>B</td>
</tr>
<tr>
<td>Denver</td>
<td>B</td>
</tr>
<tr>
<td>TEACCH</td>
<td>C</td>
</tr>
<tr>
<td>« Integrative » (« Exchange and development ») (Tours)</td>
<td>AE</td>
</tr>
</tbody>
</table>

AAA: Applied Behavior Analysis
Interventions not recommended by the HAS (1)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Conclusion of the HAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods inspired by psychoanalytic principles</td>
<td>No scientific evaluation, no consensus of experts</td>
</tr>
<tr>
<td>Institutionnal psychotherapy</td>
<td></td>
</tr>
</tbody>
</table>
## Interventions not recommended by the HAS (2)

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Conclusion of the HAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Son Rise</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>3i</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>Feuerstein</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>Padovan</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>Flortime / Greespan</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>Doman – Delacato</td>
<td>Not recommended (AE)</td>
</tr>
<tr>
<td>CO2-O2 + another method</td>
<td>Not recommended (AE)</td>
</tr>
</tbody>
</table>
RECOMMENDATION GOOD PRACTICE ASD


3. Centre Fédéral d’Expertise des Soins de Santé (KCE), Belgique, 2014
Six main contributions of NICE (U-K)

1. Power of autism
2. Behavioral and conduct disorders
3. Associated disturbances and comorbidities
4. Ways to improve impact of autism on families and other relatives
5. Side effects of interventions
6. General organization of care and teaching deliveries
Recommendations by KCE (Belgium)

1. Full availability of both home and residential cares, with legal opposability against social security
2. Rights to decide always possible for parents
3. Both options (adapted normal and special teaching) available
4. Continuing education and support available for professionals
5. Systemic concertation (von Bertallanfy)
6. Research programs about PECS, LEAP, ESDM – Denver, TEACHH, therapies language and speech, neuropharmacology
TOWARDS A GLOBAL CONSENSUS

- Recommendation for good practice
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Sigmund FREUD
"On Narcissism"

"WE MUST RECOLLECT THAT ALL OUR PROVISIONAL IDEAS IN PSYCHOLOGY WILL PRESUMABLY ONE DAY BE BASED ON AN ORGANIC SUBSTRUCTURE »
½ of the cases

- Conspicuous enhancement of communication and I.Q.
- Significant improvement of adaptative behaviors
Methodological research about cognitive and behavioral methods

*NICE, UK (2013) – KCE, BE (2014)*

- Evaluation of cognitive and behavioral methods with new tools (Thurin – Cohen – Falissard)
- Systemic approaches Bertalanffy (Wintgens)
- New research about affective, systemic and familial aspects of cognitive, developmental and behavioral methods for ASD
A Framework for Establishing Evidence-Based Standards

- Mary Jane England, Adrienne Stith Butler, and Monica L. Gonzalez, Editors
- Committee on Developing Evidence-Based Standards for Psychosocial Interventions for Mental Disorders; Board on Health Sciences Policy
- Institute of Medicine

The US National Academies Press, 2015
Institute of Medicine, USA, 2015

- Engage Consumers
- Strengthen Evidence Base
- Identify Elements of Interventions
- Conduct Independent Systematic Reviews to Inform Clinical Guidelines
- Develop Quality Measures
- Implement Interventions and Improve Outcomes
Institute of Medicine,
USA,
2015

Unique Specific Element
e.g., cognitive restructuring

Manualized Psychosocial Intervention I
Cognitive Processing Therapy for PTSD

Cognitive-Behavioral Therapy

Shared Specific Elements
e.g., explore attempts to avoid distressing thoughts or feelings

Non-specific Elements
e.g., engaging the client

Unique Specific Element
e.g., 45-minute exposure to memory of trauma

Manualized Psychosocial Intervention II
Prolonged Imaginal Exposure for PTSD

Unique Specific Element
e.g., explore fantasy life

Manualized Psychosocial Intervention III
Brief Psychodynamic Therapy

Psychodynamic Theory
The developmental process for quality measures, from Byron et al. 2014
Continuing Education and certification

Cognitive-Behavioral Therapy  Clinicians certified through competency-based training and assessment  Fidelity assessed through electronic health record documentation and periodic review of audiotaped sessions using a standardized assessment tool
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Prévalence du diagnostic

By some counts, autism diagnoses have climbed steadily since the 1970s. Some research has found explanation for more than half of the rise (right).

Dramatic enhancement of prevalence of ASD


- CMV (???)
- Valproate (???)
- Premature births (???)

*Children who formerly would have been diagnosed solely with mental retardation
Myelinated fiber bundles and cell soma columns, Planum temporale

Buxhoeveden & Casanova
Columnar pathology in autism
Casanova et al., Neurology, 2002

- 9 brains of autistic patients and 9 controls
- Autism Research Foundation
- Margaret Bauman and Tom Kemper, BU & Yakovlev Collection, AFIP
- Computerized imaging program
- Areas 9 [prefrontal], 21 & posterior 22 (Tpt) [temporal]
Neocortical columns in ASD

- **Columnar width**
- **Peripheral neuropile space**
- **Interneuronal distance**
- **Compactness**
- **Gray level index**

In brains of autistic patients, cell columns:

- More numerous
- Smaller
- Less compact
- Reduced neuropil space in periphery

Casanova *et al.*
Brain development and ASD

- Neural migrations
  - vertical columns
  - [reelin]
  - VIP
  - [prenatal serotonin]

- Glutamatergic synapses: production & stabilization
  - transient serotoninergic innervation (*5HT1A through VIP, BDNF*)
  - neuroligins
  - [apoptotic]
  - transcription
  - background noise

- NMDA diseases
- Chemical reversible changes of DNA (by methylation) and of surrounding proteins (histones) -> modification of activity and gene expression
- Existence of an epigenetic code combining epigenetic marks (???)
Genes could be activated or inactivated by psychological factors
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CONSENSUS FOR THE CHILD

The power of autism
Two forms of state-of-art statements

NIH (OMAR) and HAS (France) consensus statements

- New information
- Recent or ongoing medical research
- No specific algorithms or guidelines for practice

Reevaluation of medical practices: algorithms and guidelines

- Cost
- Available expertise
- Available technology
- Local practice circumstances
Frequent failures of well planned consensus conferences

- Nonadherence
- Clinical inertia
- Therapeutic inertia

J.D. Allen et al., JMCP, 2009

**TABLE 1** Factors Contributing to Apparent Clinical Inertia

<table>
<thead>
<tr>
<th>Clinician</th>
<th>Patient</th>
<th>Health System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Failure to initiate treatment</td>
<td>Medication side effects</td>
<td>No clinical guideline</td>
</tr>
<tr>
<td>Failure to titrate treatment to goal</td>
<td>Too many medications</td>
<td>No disease registry</td>
</tr>
<tr>
<td>Failure to set clear goals</td>
<td>Forgetfulness</td>
<td>No visit planning</td>
</tr>
<tr>
<td>Underestimation of patient need</td>
<td>Cost of medication</td>
<td>No active patient outreach</td>
</tr>
<tr>
<td>Failure to identify and manage comorbid conditions such as depression</td>
<td>Denial of disease</td>
<td>No decision support</td>
</tr>
<tr>
<td>Insufficient time</td>
<td>Denial of disease severity</td>
<td>No team approach to care or lack of care coordination</td>
</tr>
<tr>
<td>Insufficient focus or emphasis on goal attainment</td>
<td>Perception of low susceptibility</td>
<td>Poor communication between clinician and office staff</td>
</tr>
<tr>
<td>Reactive rather than proactive care</td>
<td>Absence of disease symptoms</td>
<td></td>
</tr>
<tr>
<td>Mistrust of clinician</td>
<td>Mistrust of clinician</td>
<td></td>
</tr>
<tr>
<td>Poor communication with clinician</td>
<td>Low health literacy</td>
<td></td>
</tr>
<tr>
<td>Low health literacy</td>
<td>Mental illness, depression, substance abuse</td>
<td></td>
</tr>
<tr>
<td>Lifestyle</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- Ex cathedra medical experts: often dangerous
Minicolumns

Macrocolumns

> « Segregate »

> « Hypercolumn »

Variants

- Somatosensory cortex
- Visual cortex
Epigénétique

place centrale aux confins

<table>
<thead>
<tr>
<th>Sérieux risques scientifiques</th>
<th>Attentes contre radicalisme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Argument anti-darwiniste utilisé par certains</td>
<td>Gènes: simple ressource transmise héréditairement</td>
</tr>
<tr>
<td>Ambiguïté et confusions science-société</td>
<td>Comportements ne se limitent souvent pas à action directe d’un ou quelques gènes</td>
</tr>
<tr>
<td>Rôle majeur environnement</td>
<td></td>
</tr>
</tbody>
</table>
Effet boomerang

- Eugénistes qui ont précédé 2ème guerre mondiale
- Perspectives mirobolantes du séquençage
Discussion « philosophique » de l’épigénétique

- Illusion anti-cartésienne ou anti-moniste ?
- Retour de Lamarck (hérédité de caractère acquis) ?
- Resoumettre le corps à l’esprit et à la volonté ?
- Revitaliser la "psychodynamique" et la psychosomatique
Au-delà des gènes

- Environnement
- Education, enseignement, stimulations, les mémoires
- Epigénétique (méthylation, histones)
- Science fiction
  - Transmission de l’acquis
  - Code épigénétique
Le combinatoire génétique et environnemental a des conséquences extrêmement variables dans l’espace et dans le temps.