NICE GUIDANCE AND AUTISM

HILARY CASS
Evelina Children’s Hospital
Guy’s and St Thomas’ NHS Foundation Trust
GUIDANCE TIMETABLE

- Scoping workshop 07 May 2009
- Consultation on scope 9 Jun - 7 Jul 2009
- Consultation on guideline 28 Jan - 25 Mar 2011
- Pre-publication check 05 Jul - 26 Jul 2011
- Publication September 2011
GENERAL POINTS ABOUT GUIDELINE DEVELOPMENT

• Long in gestation

• Many hours of debate, discussion, redrafting....

"Yeah Doc, I think my wife is ready to have the baby, her contradictions are only 30 seconds apart now."
MANY HOURS SPENT REVIEWING THE EVIDENCE
BUT WHAT ABOUT NATIONAL AUTISM PLAN FOR CHILDREN?

• Joint venture
  ⇒ National Autistic Society
  ⇒ RCPsych & RCPCH
  ⇒ Backing of All Party Parliamentary Group

• 2001: National Initiative for Autism: Assessment and Screening (NIASA)
• 2003: NAPC released
3 LEVELS OF EVIDENCE

- **Grade A:** At least one randomised trial
- **Grade B:** Well conducted clinical trials but no randomised clinical trials
- **Grade C:** Expert NIASA Working Group recommendation

A majority of the recommendations Grade C
FOUR AREAS ADDRESSED

• Identification
• Assessment
• Diagnosis
• Intervention
IDENTIFICATION

• No whole population screening
• Training of professionals in ‘alerting’ signals
• Regular opportunities for parents to discuss developmental concerns
• Each area to audit its age of detection / diagnosis
ASSESSMENT

• Three stages
  ⇒ Stage 1: General multi-disciplinary assessment (GDA)
  ⇒ Stage 2: Multi agency assessment (MAA)
  ⇒ Stage 3: Pathway & access for referral to tertiary assessment if needed

• Timeframe
  ⇒ Response to referral within 6 weeks
  ⇒ GDA to plan of action within 13 weeks
  ⇒ Referral for MAA to full care plan within further 17 weeks
DIAGNOSIS

- Trained lead clinician in every area
- MAA to include medical, physical, psychometric, educational, motor, language and communication, behavioural and mental health assessments
- Observation across more than 1 setting
- Key worker allocated to each family with diagnosed ASD
INTERVENTION

• Programme to be discussed with family within 6 weeks of end of MAA
• Pre-school children 15 hours per week of appropriate intervention
• Every area to have an ASD-trained teacher
• Every family to have care manager
UNDERLYING PRINCIPLES OF NAPC

- Prevalence estimates at time of publication – 60 per 10,000 ASD
- Standards set for time frames to assessment, diagnosis, intervention
- Clear requirement for multi-disciplinary expertise
- Resource implications highlighted
- Strong emphasis on broader staff training requirements
- Strong emphasis on audit and strategic service planning
ISSUES RE IMPLEMENTATION

• Increasing recognition / referral rate

• No specific resource allocated

• Payment system for NHS services under revision at that time (PbR)
WHAT HAS BEEN ACHIEVED?

- Questionnaire survey UK CDTs
- Response rate 149/243 (61%)
- Comparison 2007 to 2001 (NIASA data)

## RESULTS OF CDT SURVEY (1)

<table>
<thead>
<tr>
<th>Service</th>
<th>2001</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDT approach</td>
<td>48%</td>
<td>93%</td>
</tr>
<tr>
<td>ASD assessment protocol</td>
<td>32%</td>
<td>54%</td>
</tr>
<tr>
<td>Timescale for completion</td>
<td></td>
<td>36%</td>
</tr>
<tr>
<td>Meet NAPC timeframe</td>
<td></td>
<td>49% of 36%</td>
</tr>
<tr>
<td>Standardised Dx interview</td>
<td>14%</td>
<td>50%</td>
</tr>
<tr>
<td>Published observational asst</td>
<td>14%</td>
<td>56%</td>
</tr>
<tr>
<td>ADOS</td>
<td></td>
<td>88% of 56%</td>
</tr>
<tr>
<td>Written asst report to parents</td>
<td></td>
<td>92%</td>
</tr>
<tr>
<td>Written plan to parents</td>
<td></td>
<td>46%</td>
</tr>
</tbody>
</table>
RESULTS OF CDT SURVEY (2)

- Only 9% of CDTs received new funding to support NAPC
- 74% felt their services effective
- Age of children seen
  - Preschool – 87%
  - Primary school – 77%
  - Secondary school – 64%
THE REALITIES

Remains hard to stay on top!!
WILL NICE GUIDANCE HAVE MORE TEETH?

"Ok, so it's carved in stone, but still open to interpretation, right?"

Copyright © 2010 R.J. Romero. www.hipaa cartoons.com
At the end of the money,
I always have some
month left.
PRINCIPLES AND CONTEXT OF NICE GUIDELINES

- Concerned with
  ⇒ Recognition
  ⇒ Referral
  ⇒ Diagnosis

- Underlying data
  ⇒ ASD occurs in 1% of child population
  ⇒ 70% have at least one other impairing psychiatric disorder
  ⇒ 50% have IQ < 70
KEY PRIORITIES FOR IMPLEMENTATION

• Guideline currently 249 pages
• Focus for discussion today
  ⇒ New areas
  ⇒ Areas which may have teeth
  ⇒ Area which raise challenging questions / issues
Local ASD strategy group

- Group to have representation from all agencies including voluntary and service users
- Lead professional to be appointed with responsibility for pathway
  - Improving early recognition
  - Making sure all professionals aware of pathway
  - Smoothing transition to adult services
- Access to ASD team through single point of entry
Tools to support recognition

• 4 tables
  ⇒ Tables 1-3: Alerting signs for preschool, primary and secondary school age children
  ⇒ Table 4: Risk factors for autism
• Urgent referral of children with history of regression
EXAMPLES OF AGE-DEPENDENT BEHAVIOURS

Literal understanding, failure to understand metaphors may become apparent later

Every Thursday, as usual, John took the rubbish out
IMPORTANT ‘TRAPS’ RE RECOGNITION

• Girls present differently from boys
• Children of secondary age may have masked symptoms with coping mechanisms and / or supportive environment
• ASD may be missed in ID
• Children may have had apparently normal early development, make good eye contact etc.
OTHER DIFFICULT DIAGNOSES:
NORMAL CHILDREN & TEENAGERS

My God Jack! Have we been burgled?

No – the grandchildren came round

Pete’s just going through his rebellious phase!
How readily would you be able to implement a strategy group in your area?

What impact would such a group have on your ASD service?
ASD MULTIDISCIPLINARY ASSESSMENT TEAM

 Capability to assess:

- Children with learning disability
- Children with co-morbid MH problems
- Children with motor / sensory impairment

Children across age range
MAKING PREDICTIONS AGAIN
A FLUCTUATING BASE

Severity of feature

Child’s level
Diagnostic cut-off
Functional impairment

Age

A
B
C
ASD DIAGNOSTIC ASSESSMENT

• Within 3 months of referral
• Case co-ordinator as point of contact
• Diagnosis based on ICD-10 / DSM-IV
• Need to consider other differential / co-morbid diagnoses:
  ⇒ Neurodevelopmental
  ⇒ Neuropsychiatric
  ⇒ Regressive (e.g. epileptic encephalopathy)
  ⇒ Other (e.g. selective mutism)
INVESTIGATION

- None routine!
- Consider genetics, EEG as indicated

Julie couldn’t help but have nagging doubts about the MMR vaccine.
DIFFICULT DIAGNOSES

- CA < 24 months
- MA < 18 months
- Lack of information re early life
- Complex co-morbid mental health problem
DISORDERS WITH POSSIBLE FRONTAL PATHOLOGY

- Autism
- Aspergers
- ADHD
- Dyspraxia
- DAMP
- Tourette’s etc.

Common to all - social cognition deficits
COMORBIDITY, NOT AN ‘EITHER / OR’….

• Disorders common in AS / autism
  ⇒ ADHD (prepubertal children)
  ⇒ Depression (adolescents and adults)
  ⇒ Affective disorder
  ⇒ Anxiety
SYNDROMES OF ‘DISINHIBITION’

ADHD

Frontal lobe (impulsivity)

Tourette’s

Frontal lobe + basal ganglia (movement disorder)

OCD

DISINHIBITION

- Distractibility
- Fidgetiness
- Unfocused attention
- Poor activity control

DISINHIBITION

- Obsessive thoughts
- Poor task focus
- Less distractibility
- Fast associations
OTHER DISINHIBITION SYNDROMES

The David returns from a trip to the USA
Importance of impulse inhibition
How well trained do most people feel to make confident mental health differential diagnosis?

Should there be more CAMHS training in neurodisability Level 3 programme?
I hate repeating gossip—but really, what else can you do with it?
INFORMATION

- Clear explanation of diagnosis
- Profile
  - Intellectual ability
  - Language and communication
  - Fine and gross motor skills
  - Adaptive behaviours
  - Mental / emotional health
  - Sensory sensitivities
  - Behaviour likely to affect participation
COMMUNICATION

- Written report to family and key professionals all agencies
- Follow up appointment ASD team within 6 weeks
- Ensure profile available to education
- Contacts for support groups
- Contacts for transition, as appropriate
IS DSM-V GOING TO HELP US?

Severity rating + more simplified diagnostic framework

“No, you don’t get to pick one from each column!”
Functionally impairing social deficit currently

No

Functionally impairing social deficit previously

No

In wrong clinic

Yes

Watchful waiting

Consider differential diagnoses of social impairment

No

Clinical assessment +/- ADI and ADOS

No

Meets criteria in 3 domains

Autism

Yes

Meets criteria < 3 domains

Autistic spectrum

Yes

Sub-clinical scores on formal tests

Other diagnosis

?
PROPOSALS (1): Diagnosis

• One spectrum called Autistic Spectrum Disorder
• No differentiation of PDD-NOS, Asperger syndrome etc.
• Diagnosis purely on behavioural symptoms
• Can occur with any other diagnosis
  ⇒ Rett syndrome
  ⇒ Intellectual disability
  ⇒ Language disorder
PROPOSALS (2): Two domains instead of three

- **Social communication**
  - Basic deficits in verbal & non-verbal communication
  - Lack of social reciprocity
  - Lack of interest or difficulty establishing relationships with peers

- **Fixated interests, repetitive behaviours**
  - Repetitive behaviours, sensory anomalies, mannerisms etc.
  - Insistence on sameness, rituals
  - Fixated interests
PROPOSALS (3): Exemplars for different age / language levels

• Social communication
  ⇒ Preschool / Child / Adolescent
  ⇒ Non-verbal or single words / phrases / fluent

• Fixated interests / repetitive behaviours
  ⇒ Preschool / Child / Adolescent
  ⇒ Non-verbal or single words / phrases / fluent
<table>
<thead>
<tr>
<th>PROPOSED DSM-V SEVERITY</th>
<th>Social Communication</th>
<th>Fixated Interests and Repetitive Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most severe ASD</td>
<td>Minimal or no social communication</td>
<td>Nearly constant, complete preoccupation, strongly resists interference with ritual</td>
</tr>
<tr>
<td></td>
<td>Some social communication but interactions noticeably disturbed</td>
<td>Frequent and interfering rituals, repetitive behaviors and fixated interests</td>
</tr>
<tr>
<td>Less severe ASD</td>
<td>Clear impairments in social communication. Meets all diagnostic criteria including symptom severity greater than threshold</td>
<td>Occasional rituals, repetitive behaviors and fixated interests; some interference</td>
</tr>
<tr>
<td>Subclinical AS Symptoms</td>
<td>Has some symptoms from one or both domains but no significant interference or impairment.</td>
<td>Odd mannerisms, some excessive preoccupations but distractible, may have ritualized behaviors but they don’t interfere with daily activities</td>
</tr>
<tr>
<td>Normal Variation</td>
<td>Socially isolated or “awkward”</td>
<td>Some ritualized behaviors and preoccupations but these are normal for developmental stage and cause no interference</td>
</tr>
</tbody>
</table>
SOME FINAL THOUGHTS

• Autism is a disorder with some clear biological substrates
• Diagnosis is not based on biologically derived criteria, but on an operational consensus
• Operational definitions have both value and limitations
• Living with disorders of social cognition is a reality; it may not always be adequately described by operational definitions
• Professionals, not biology, create boundaries and constraints.
“I will now take questions from the floor”