An Update on Aspects of Autism for Primary Care Providers: PART 2

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Medical Home Model

• **AAP: for children with special needs**
  - Care that is
    • Comprehensive, coordinated, accessible, family centered, sensitive
    • Model ➔ better primary care
    • For children with autism care is
      - Often fragmented, trouble with accessing services, primary care providers have little knowledge, frequent use of ED as source of care, failure to look at ‘big picture’ issues (e.g. dental visits)
Medical home – cont’d

• **A growing body of work on effectiveness**
  - Greater access to specialty care
  - Greater parent/caregiver satisfaction
  - Reduction in ED use
  - Some potential for financial incentive
  - Limitations
    - Lack of training
    - Time and $ constraints
    - Geographic variations in resources
Eating And GI Problems

- Unusual food preferences/sensitivities
- Obesity
- Pica
- Constipation
- Many dietary interventions but..
- Several reviews now show
  - Evidence for GFCF diet and vitamins weak
  - No evidence of specific GI issues unique to autism
Dental care

- **Frequently avoided!**
  - Importance of starting early!
  - Prevention of cavities
  - Good oral care

- **If dental care avoided**
  - Common difficulties in adolescents often requiring general anesthesia!
  - In nonverbal individuals onset of face slapping can signal dental issues (or ear infections)
Safety and Bullying

• **Accidental injury**
  – Most common cause of death
  – 2X typical children
  – 40% bolt

• **Bullying**
  – At least twofold increase
  – Risk with additional problems
  – May present in primary care settings
Age related issues: Preschool

- **Diagnostic assessments**
- **Foundation for continuing health care**
  - Medical home
  - Services
  - Screening for problems
  - Coordination role
  - Transition to preschool, school programs
  - Behavior problems may increase
  - Diagnosis usually clear by age 3
  - < 5 years is time for greatest gains
  - NOT every child gains
Age relates issues: School Age

- Preventative care & Routine visits
- Dental care
- Vaccinations
- Be on the look-out for
  - Developing obesity
  - Pharmacological intervention side effects
  - Safety (bolting)
  - Bullying
Age related Issues: Adolescents and Adults

- Limited info on medical care/problems available – essentially none on aging!
- Appears to be increased risk relative to
  - Use of meds, sedentary life style, social isolation for
    - Obesity, probably hypertension
    - Among the more cognitively able
      - Increased risk of anxiety and depression & Bullying
- Issues with insurance coverage and support
Drug Treatments

• **Importance of Double blind, placebo controlled studies**
  - Major “placebo effect”

• **Medications most frequently studied**
  - Risperidone and newer 2\textsuperscript{nd} generation neuroleptics – work well and quickly
  - SSRIs – used for anxiety/depression, rigidity but seem to work less well in children, better in adolescents and adults

• **Side effects and balance of risk and benefit**
RUPP Autism Network: Irritability Scale

![Graph showing ABC Irritability (N=101) over weeks for Risperidone Mean and Placebo Mean.](image-url)
Other medications

• Essentially used to treat associated conditions
  – Attention ➔ stimulant and nonstimulants
  – Anxiety/depression ➔ SSRIs
  – Mild sedatives ➔ Benadryl, benzo’s

• Caveats
  – Don’t treat bad program with meds!
  – Side effects common
    • Stimulant and SSRI’s ➔ agitation
    • Weight gain with atypical neuroleptics
Vaccines and Autism

- **Lancet article (1998) MMR→Autism**
  - NO subsequent study supports this
  - Paper withdrawn by Lancet

- **Thimerosal, a mercury containing preservative in vaccines also implicated**

- **BUT many parents avoid vaccines**
  - risk for preventable diseases
  - Already seeing resurgence in US/UK
Autism Interventions

• **Intervention 1950-1980**
  - psychodynamic models – AKA blame the parents (IM US few went to public school)
  - Studies began to suggest importance of structured treatment
  - Parent founded schools/support

• **In US – major change with PL 94-142 (1975)**

• **Importance of planned, intensive intervention to cope with social difficulties**
Why is the label important?

• **Access to services in school**
  – Specific label may not be immediately needed BUT be careful, this isn’t an excuse
  – Schools are MANDATED to provide services including assessment starting at age 3
  – Before age 3 another state agency responsible

• **State requirements vary**
  – Widely and wildly
Several sets of practice guidelines have appeared

- Filipek et al. (2000) Neurology (screening only) (Neurol.55:468-479)
- AAP recommendations (2007) (mostly focus on screening)
- NICE Guidelines (2011) – Available online
- AACAP Guidelines currently in (endless) revision
Model Programs

- **Background**

- **NRC report**
  - Structured intensive intervention
  - Commonalities (and differences) in programs
  - NOT every child gets better
  - As a group improved/improving outcomes with early intervention

- **Some interesting issues**
  - University based/affiliated
  - Intensive
    - Average about 25 hours a week
Evidence Based Interventions

- A long and interesting history
- First practice guidelines in 1999
  - A number now available
  - Complexities given
    - The nature of autism interventions
    - The diversity of disciplines involved
    - The range of syndrome expression in autism
    - Nature of EBT
Model programs

note: evidence base varies!

- **ABA** – based on learning research
  - Many papers (case studies)

- **Developmental Models**
  - Rogers – Denver/Early Start model
  - Greenspan – Floor time

- **Pivotal Response** –
  - Koegel – hybrid methods

- **Eclectic models**
  - TEACCH

- **Many similarities and some differences**
Developmental issues in treatment

Minimize the impact of autism
Maximize developmental gains
A word about best practices!

- Various levels of evidence
  - RCT and meta-analyses ➔ uncontrolled studies ➔ case report, anecdote
- Different guidelines use different approaches
- Evidence based medicine
- Evidence based practice
- Issues
  - Selection of subjects, nature of research
  - Potential for ‘catch 22’
  - Some studies have never been done but the intervention is accepted!
Evidence Based Interventions

• A long and interesting history

• First practice guidelines in 1999
  – A number now available
  – Complexities given
    • The nature of autism interventions, diversity of disciplines; range of syndrome expression in autism

• Nature of EBT
  • Note: differences in standards, methods, etc. Sample selection issues

• Evidence based practices and treatments
Never been proven to work in a RCT!
Outcome – two snapshots

First studies

Next wave!

Data adapted from Howlin, 2005
Good: independent, Fair: Semi-independent, Poor: 24/7 care
Good news!: Colleges grew out of monasteries!

- Provide order and structure
- Use routines and schedules
- Many things available
  - Food, books, entertainment
- You can minimize social interaction!
Mental health supports

• Most adults have no access to specialist intervention

• Higher than expected rates
  – Anxiety, depression

• High rates of medical use (including those with higher IQ)
  – Esbenshagen et al. 2009
    • 88% on one medicine
    • 40% on 3 or more
Emerging and Nonestablished Treatments:

- Understanding single-case “cures”
- Intrinsic limitations
  - case reports and the news media
  - Mark Twain’s 3 kinds of stories
  - Bias for positive reports
  - Minimal attention to unrelated but (important) issues
  - Typically little independent assessment
  - Regression to the mean (fluctuation over time)
  - Some children will do well without (or despite) treatment
CAM (complementary and alternative treatments)

- Very frequently used
- Complimentary (in addition to proven treatment)
- Alternative (instead of proven treatments)
- LIMITED Sources of information for parents AND professionals
- BOOKS
  - Controversial therapies for developmental disabilities
- Practical guidance on CAM
Happy post holidays!
References 1

- IbaÑez, L. V. et al. (2014) *Handbook of Autism and Pervasive Developmental Disorders*, John Wiley & Sons, Inc. vol 2 585-608,
References 2

- US PHS Screening Recommendations http://www.uspreventiveservicestaskforce.org/