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)

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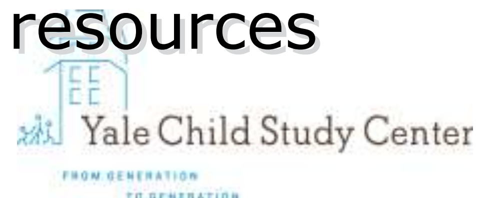
Medical home – cont'd

- **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

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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)

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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

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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

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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

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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**

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Drug Treatments

- **Importance of Double blind, placebo controlled studies**
  - Major "placebo effect"
- **Medications most frequently studied**
  - Risperidone and newer 2nd 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**

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RUPP Autism Network: Irritability Scale

ABC Irritability (N=101)

ABC Irritability Total.

30.0
25.0
20.0
15.0
10.0
5.0
0.0

0 2 4 6 8

Week

Risperidone Mean
Placebo Mean

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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

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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➔**

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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

Using Evidence Based Treatments in Practice

- **Several sets of practice guidelines have appeared**
  - Volkmar et al (1989) AACAP (JAACAP 38:32S-54S)
  - Filipek et al. (2000) Neurology (screening only) (Neurol.55:468-479)
  - AAP recommendations (2007) (mostly focus on screening)
  - NICE Guidelines (2011) – Available on Line
  - AACAP Guidelines currently in (endless) revision

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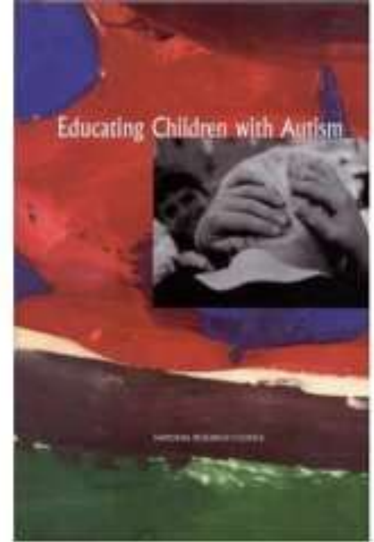
Model Programs



- **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

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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**

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Never been proven to work in a RCT!

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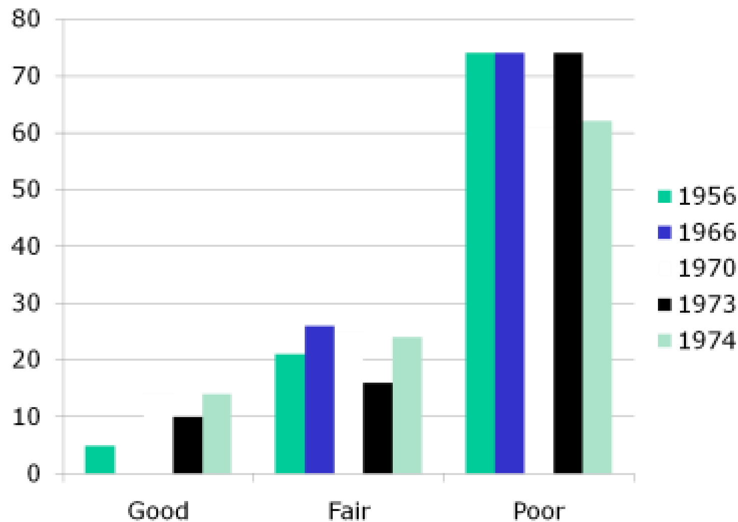
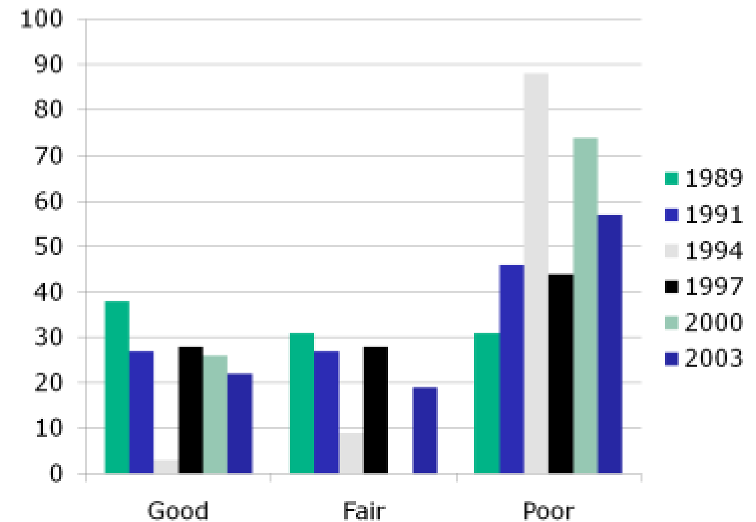
Outcome – two snapshots

First studies



Next wave!



Data adapted from Howlin, 2005

Good: independent, Fair: Semi-independent

Poor: 24/7 care

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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!**

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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)**
  - Esbensen et al. 2009
    - 88% on one medicine
    - 40% on 3 or more

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Emerging and Nonestblished Treatments:’

- **Understanding single-case “cures”**
- **Intrinsic limitations**
  - case reports and the news media
  - Mark Twains 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

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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!

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