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The Changing Face of Autism:  
A Developmental Perspective

Fred R Volkmar, MD, Irving B. Harris Professor of Child Psychiatry,  
Psychiatry, Pediatrics, and Psychology at Yale University, Child Study  
Center and Editor, Journal of Autism and Developmental Disorders

# The Changing Face of Autism: A Developmental Perspective

**Fred R Volkmar MD**

Irving B. Harris Professor and  
Director, Yale University Child Study Center  
& Goodwin Professor of  
Special Education, Southern Connecticut  
State University



[www. Childstudycenter.yale.edu](http://www.Childstudycenter.yale.edu). or

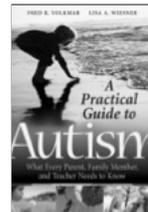
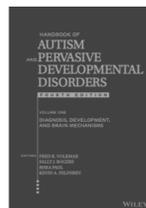
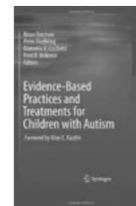
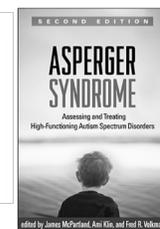
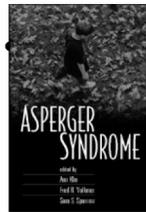
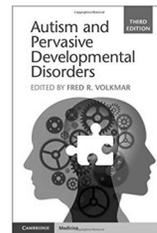
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1

# Conflicts of Interest

- **NIMH Grant HP50  
MH115716**



2

# Welcome to 2019!

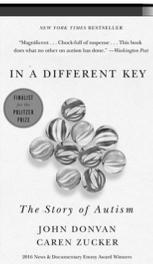


## Overview

- **Some good and some less good news**
- **Overview of outcome in autism**
  - In relation to various issues
- **Developmental in several sense**
  - Of individuals AND of the field
- **What does research tell us?**
- **Challenges for adolescents and adults**
  - vocational, daily living, mental health and legal challenges
- **What are the gaps in knowledge?**
- **Prospects for the future**

## General principles:

- **The interaction of research with clinical work:**
  - Feb. blizzard
  - My patient's text



## Development of the field: I

- **Origins of interest**
  - Feral children
  - Institutions in 1800s
- **Leo Kanner 1943 – 1st description**
  - Autism and “insistence on sameness”
- **Asperger 1944 – “autistic personality disorder”**
  - Same word BUT more verbal, special interest, + family history
- **Effectively this sets the current tension between Narrow and Broad views!**



## What is in a name?

- **αὐτός**

- The intended sense of αὐτός is generally defined by its grammatical context. When used as a lone nominal without an article, it is generally the third person personal pronoun. When appended to a nominal and not possessing the definite article it is "self". When combined with the definite article, either appended to a nominal or on its own, it is "same".

## What's in a name? Part 2



## Giving the “A words” broader context

- **What do we know about autism and Asperger’s?**

- Early onset problems
- A ‘range’ or expression
  - “neurodiversity” and “broader autism phenotype”
  - Complicated genetics and etiology
- Cases reported LONG before Kanner or Asperger – but not recognized



9

## Why think of Autism as a learning disability

- **In the US long history of supporting people with disabilities**

- IDEA
  - Right to education
- ADA
  - Right to non-disclination, access, 504 plans, accommodations
- This movement was part of amore general ‘revisiting’ of civil rights issues in the US



- **Educators – easier to get on board!**



10

## Development of the Field I

### Important early advances

- **Autism was BRAIN BASED**
  - High rates of epilepsy,
  - Neurodiversity issues
- **Autism was strongly GENETIC**
  - First twin studies and early family studies showed strong genetic basis
  - Genetics are complex → broader range than we once thought
- **Structured educational interventions better than psychotherapy**

## Development of the Field II

- **Early MISTAKES**
  - False impression of normal IQ
    - In fact much scatter
    - most (900%) scored <70 overall
  - False impression of high parent SES
    - → blame parents (refrigerator mothers)
  - False impression no associated medical conditions
    - In fact high rates of seizures, genetics
  - False connection to childhood schizophrenia

## Development of the Field IV

- **1980s**
  - Official recognition
  - Gradual increase in awareness, research, treatment programs
- **1990s**
  - Research increased as did programs
- **2000 – present**
  - Explosion of research
  - Focus on evidence based treatments
    - NRC report



14

## Diagnosis and Epidemiology

- **Evolution of the concept**
  - Kanner (1943)
    - Autism and insistence on sameness
    - Confusion with schizophrenia, etiology
  - Asperger (1944) personality disorder
    - ? BAP
  - DSM-III (1980) – first inclusion!
  - DSM-II-R (1987)
  - DSM-IV /ICD-10
  - DSM-5



15

## DSM-5 ASD



- **ASD + SCD**
- **No subtypes/subthreshold**
- **For ASD severity dimensions**
  - Criteria
    - TWO rather than three categories
    - Monotectic in part
    - vastly reduced criteria set
      - Move from >2000 to 12 combinations
    - Some new criteria
      - Sensory issues

## Good and bad news!

- **Good News!**
  - Recognition of spectrum concept
- **Bad news**
  - Narrower concept (despite spectrum label!)

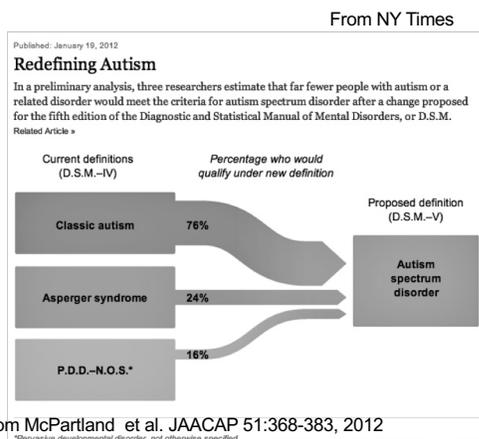


## McPartland et al 2012 JAACAP 2012

Apr;51(4):368-83.

- **Reanalysis data from 933 cases in DSM-IV field trial**
- **657 clinician dx'd asd, 276 non asd**
- **Cross walked criteria from field trial to DSM-5**
- **60.6% ASD retained DSM-5 diagnosis**
- **Specificity high (94.9%)**
- **Se varied in several ways**
  - by dx: Autism =.76, Asp=.25, PDD-NOS=.28
  - And by IQ <70 Se=.70, >70=.46

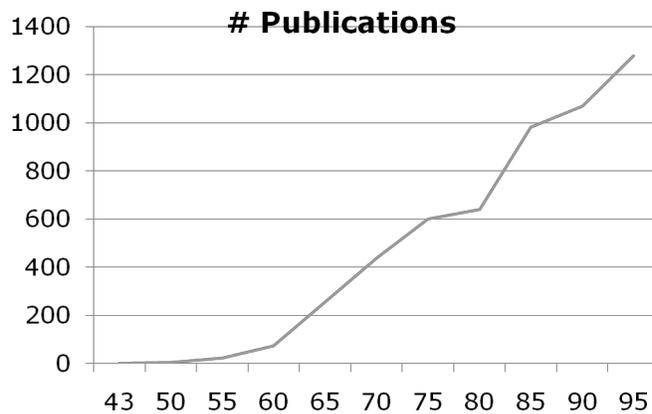
## What happens to cases?



## Research has increased

- **Both in terms of sheer volume of papers AND in sophistication of studies**
- **Now several journals devoted to Autism**
- **Quick overview of research productivity and selected research findings**

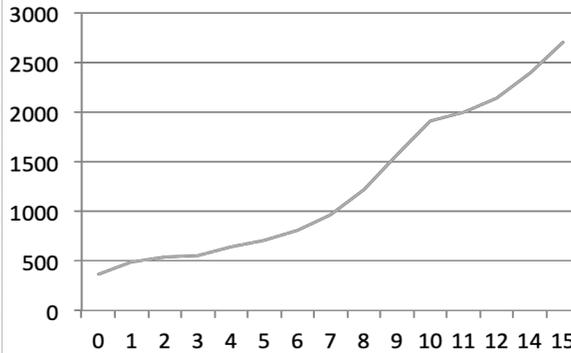
## Research Papers: 1943-1999



Data presented in 5 year blocks, source: Medline

## Research Papers: 2000-2015

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SINCE 1911



Source: Medline, note: to keep up with everything you'd have to read about 5.25 papers each day!



## Why has research increased?

- **Several reasons!**

- Intellectual interest
  - Social brain
  - Bring brain-genes-behavior together
- Social/Political reasons
  - Parent groups and Foundations
- Financial Reasons (Willy Sutton)
  - Federal funding
- Increased Media Attention
- Internet



## Research findings

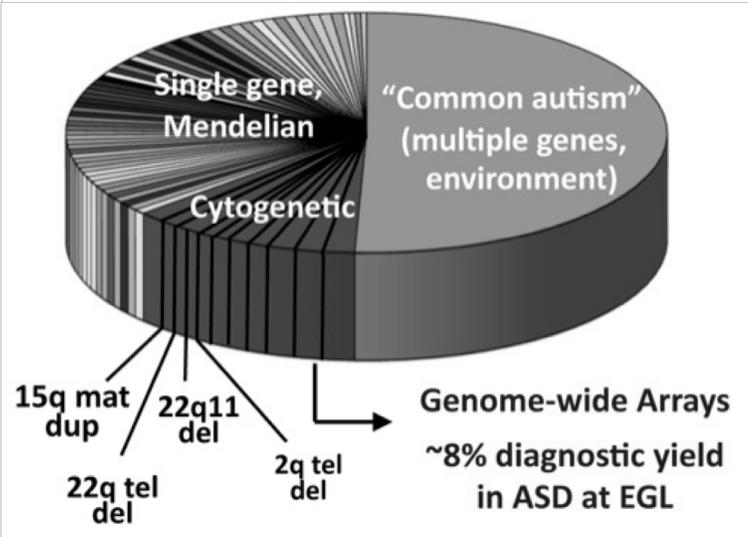
- **We know much more about**
  - Genetics of autism
  - The Social Brain in autism
  - Effective treatments
    - Earlier diagnosis →
    - Increasingly better outcomes
  - Some selective examples

## Brain studies



- **Abnormalities:**
  - Early enlarged cerebral volume followed normal volumes by age 6 – 18 years
  - CSF, white, and grey matter abnormalities, corpus callosum
  - Smaller left plenum temporale, atypical asymmetry
  - Abnormal 'minicolumns' in cortex
  - Atypical development of amygdala structure and volume related to severity
  - New approaches with fMRI to study of social brain

## Genetic 'forms' of autism



## Understanding autism

- **What is autism?**
  - It is first and foremost a disorder of social interaction associated with unusual patterns of learning and over-engagement with the nonsocial world!



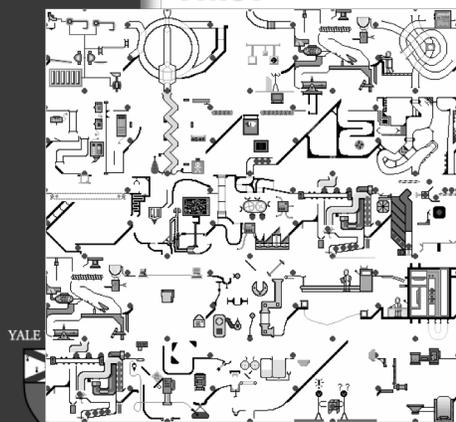
## If you have a social 'frame'

- You first and foremost are a 'people person'
- You take your lead from looking at others
  - What are they looking at, what are they feeling (face), how are they responding, how should you respond?
  - You become very good at 'multi-tasking' – ie organized skills are good since you must integrated visual, auditory (verbal and nonverbal vocal) input given context, people involved etc. etc. etc.
  - As a results – by the time you are a year or so of age you are very adapt in the social work and 'playing' in it constantly



## Which is more interesting?

**This?**



**Or This?**



Tendency to seek faces is part of the typical human experience!



32

What is the situation in autism? – It is as if people are hidden! Can u find and count the navy seals?



Pictured from left to right: LCDR Mark Simon, ETCM Eric Olin, BMC Dan Ames, BM1 Michael O'Connell, EN1 Jason Fetherman, EM2 Mark DiPietro, LT Lewis Baker, MMG Sergio Rodriguez



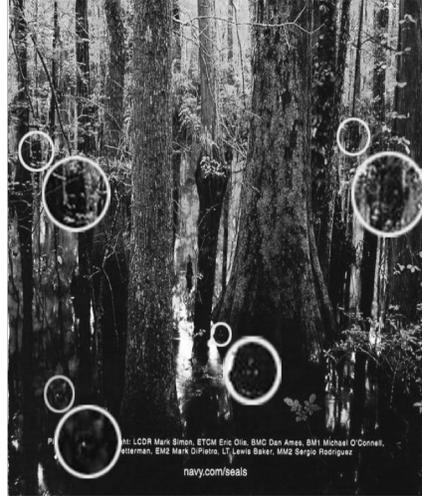
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What is the situation in autism? – It is as if people are hidden! Can u find and count the navy seals?



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LCDR Mark Simon, ETCM Eric Olin, BMC Dan Ames, BM1 Michael O'Connell, ETCM Mark O'Pinto, LT Lewis Baker, MM2 Sergio Rodriguez

navy.com/seals

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34

## Put another way!

- **If you come into the world (like most of us) with a social 'frame' to view it many things happen!**
  - People are the center!
  - Joint attention
  - Affective development
  - Desire to communicate
  - People become THE most important things in the world (starting with parents)!
- **Why might this be different in Autism**



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35

## Integrating research on social development with autism treatment

- **Growing body of work on social brain**
  - Over past decade and a half
  - Using different methods
    - EEG, eye tracking, fMRI
    - Appreciation of developmental factors
- **Development of models for understanding how early social difficulties lead to the host of difficulties seen in autism**



36

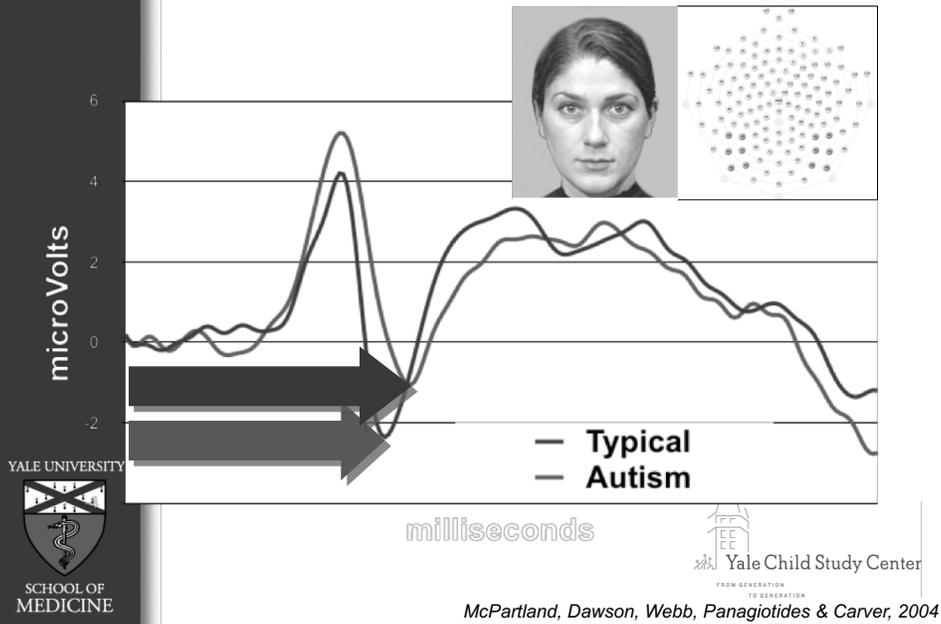
## Event-related potentials (ERPs)

Electric neural activity (EEG) recorded at scalp, **time-locked** to perceptual events to reveal evoked brain response

- **Appropriate for range of cognitive and developmental levels**
- *Millisecond* temporal resolution
  - Efficiency
  - Stages of processing
- **Economical**
- **Scalable**
- **Yields indices of social perception across lifespan**



# ERPs and faces: Autism

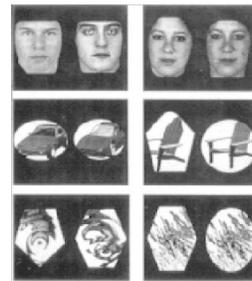


# Face Discrimination

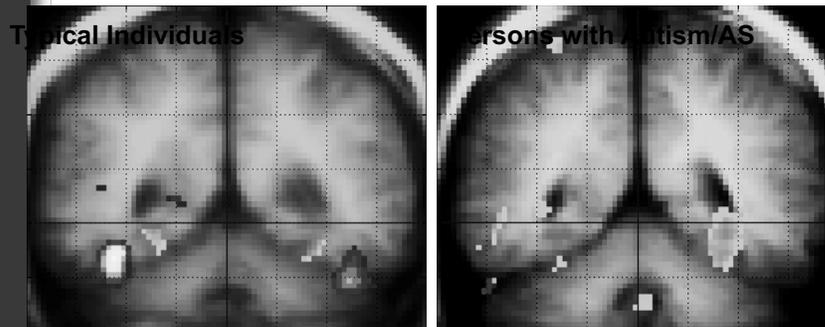
Schultz, et al. Archives of Gen. Psych., 57, 331-340

## fMRI study

- comparison to normal controls
- task: same or different:
  - people
  - objects
  - patterns
- regions of interest:
  - fusiform gyrus (face)
  - inferior temporal gyrus (objects)
- Both groups equally accurate  
-(tasks set up that way!)
- Finding now replicated >20 times

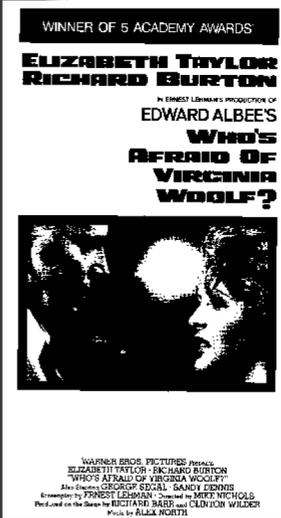


## Face Recognition: Fusiform Gyrus Group Differences



## Eye tracking research

- **Ecological validity**
  - Viewing the world with new eyes
- **Choice of subject – concerns and choices**
  - Intensely social (small number of people)
  - Minimize action/objects (aka no terminator 2)
  - Black and white initially
  - Show short segments (not entire film)
  - Chose movie about a pleasant dinner party at a small New England college with 2 faculty members and their wives



## Viewer with autism

Age: 38, FSIQ: 119,  
 ADOS-4 / ADI-R +,  
 Vineland Socialization: 69

## Typical Viewer

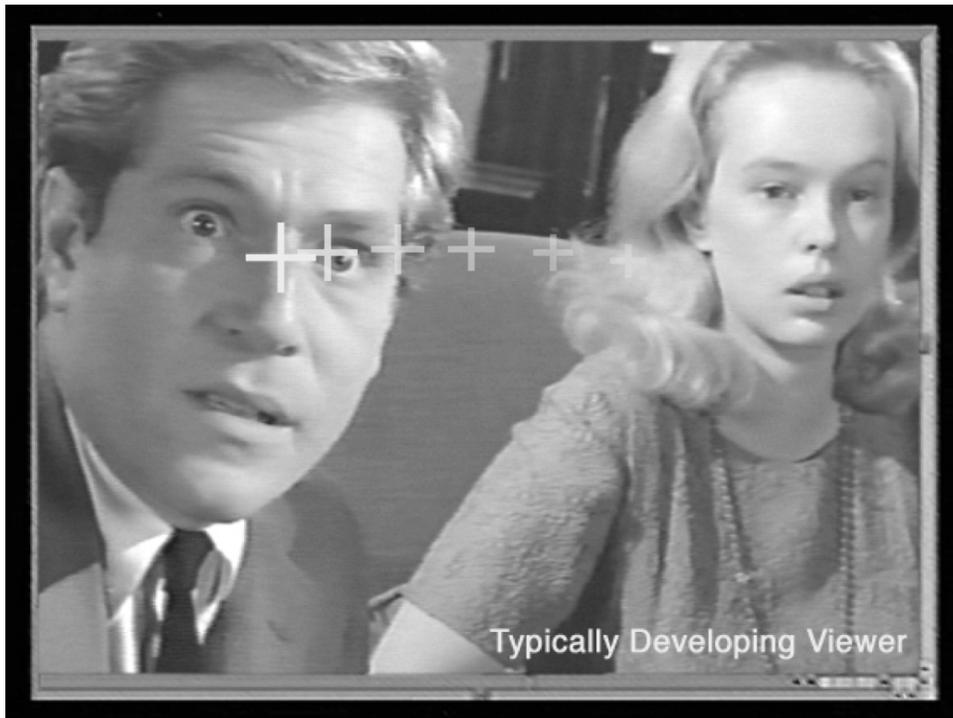
Age: 27, FSIQ: 110



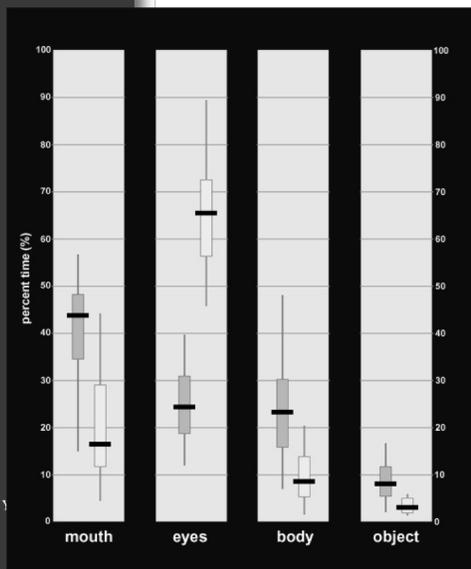
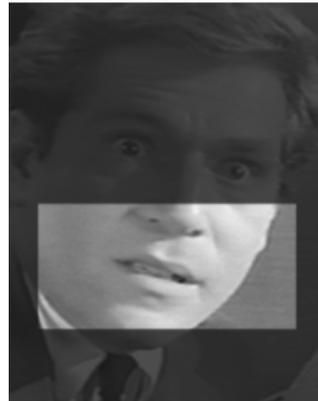
Klin et al. (2002). *American Journal of Psychiatry*, 159, 895-908.



Viewer with Autism  
 Typically Developing Viewer



Focus on mouths vs. focus on eyes → lose about 90% relevant information



## Group Results

	Autism Group	Normal Controls	t values
mouth	41.21 (14.97)	21.18 (12.12)	4.026, $p < .000$
eyes	24.63 (8.07)	65.44 (12.78)	-10.455, $p < .000$
body	24.57 (12.41)	9.65 (5.74)	4.226, $p < .000$
object	9.58 (6.46)	3.71 (2.44)	3.286, $p < .003$

values given as percent time mean (standard deviation)

Effect size (eyes):  $d=3.81$

## What Does all this mean for outcome?!

- **Development of effective evidence based treatments**
  - A range of kinds, programs, & methods
- **Increased awareness → earlier diagnosis → better outcomes (mostly)**
- **Integration of clinical work and research, e.g., we are now seeing Brain changes (EEG, MRI) in response to treatment!**

## Outcome research: Issues

- **Diagnostic issues**
  - Early studies confusion re: schizophrenia
  - More recently changes in criteria
- **Changes in intervention practice**
  - PL 94-142, IDEA
  - Improved early detection
- **Methodological problems**
  - Outcome definitions,
  - Quantifying treatments
- **Focus of 'outcome'**
  - Focus: late adolescence & young adult

## Outcome studies -

- **See Maginiati & Howlin (2019) for summary - Definitions used**

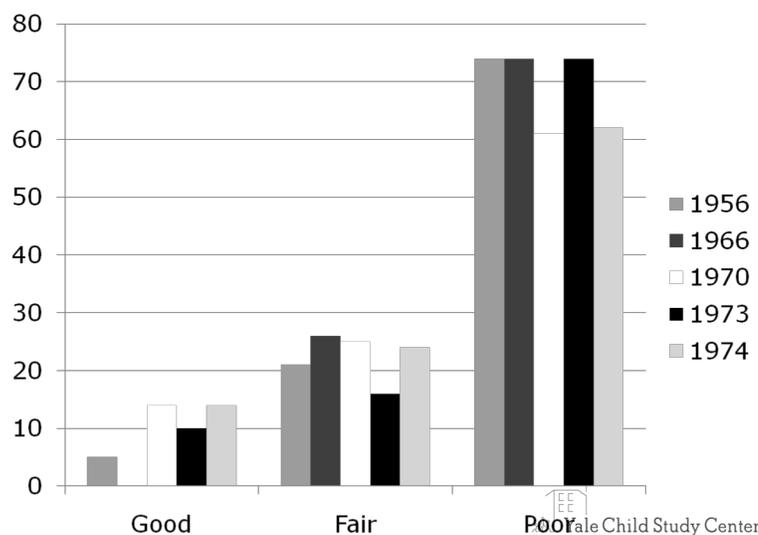
- Good: moderate to high levels of independence living/job, some friends/acquaintances
- Fair: need support at work/home but some autonomy
- Poor: living in situation with close supervision in most activities

- **Note: 'normalcy' & Optimal Outcome**



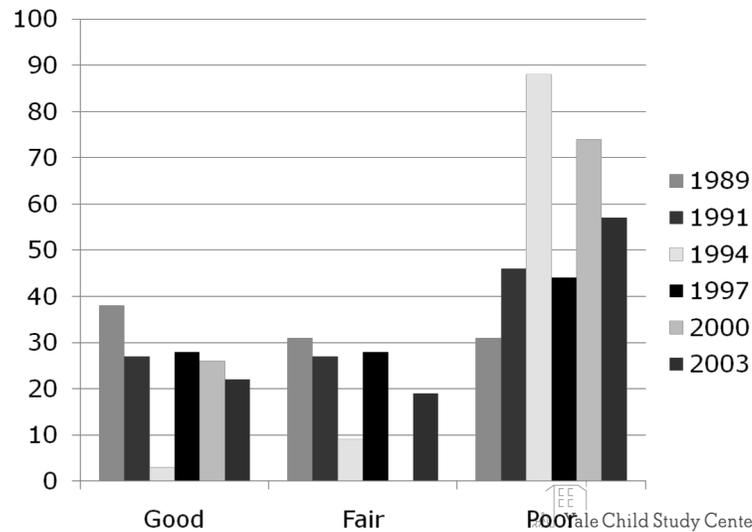
51

## Outcome studies: 1956-1974



52

## Outcome studies: 1989-2003



## Changes in outcome

- **Reflect several factors**
  - Early diagnosis and intervention → better outcome (various metrics)
  - Changes in diagnostic practice (broader definition) (some, but small contribution)
  - More and better supports
- **Issues**
  - Not every child gets dramatically better
  - Issues in matching child to treatment
  - Dearth of studies on older individuals
- **How to understand this?**

## What is a “good outcome”

- **Typically assumed to be living independently, self-supporting, & having relationships**
  - But these may be much less appropriate for more impaired individuals
  - Even for most cognitively able independence can be one that is socially isolated and uninteresting
  - Inappropriate employment can ↑ stress
  - Many wish for a range of options providing space, security, stimulation

## Limitations of available research

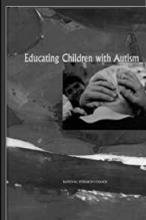
- **Paucity of research available**
  - Piven and Racins, 2011 & Mukaetovap-Ladinska, et al. 2012
  - Of 150 articles on intervention fewer than 2% had participants >20 years
  - From 2000-2010 review of 11,000 articles mentioning adults
    - only 23 focused on intervention
  - Services for adults generally much poorer than for school age children- esp. so for higher functioning adults

## Economic issues!

- **Cost of autism for adults can be high**
- **Ganz (2006)**
  - In US can be \$3.2 million (life time)
    - About \$35 billion (min) annually
- **Knapp e al. (2009)**
  - In UK total for adults £25 Billion/year
- **Increasing functional outcome has important economic as well as social policy/ethical implications**

## History: Autism Interventions

- **Intervention 1950-1980**
  - psychodynamic models – AKA blame the parents
  - Only a minority (maybe 20%) of children went to school, most ‘written off’
- **PL 94-142 (1975)**
  - Mandate for school as a right
  - Beginning of a shift in treatment
- **1980**
  - First official recognition
  - Work on interventions ↑



Evidence-Based Practices in Behavioral Health  
Series Editor: Melissa K. Singh

Margaret N. Charlop  
Russell Lang  
Mandy Rapp  
Editors

Play and Social Skills for Children with Autism Spectrum Disorder

Springer

## Autism Interventions II

- **Evidence based interventions**
  - Programs
    - ABA. Developmental, Pivotal Response, Eclectic (TEACCH)\*
  - Specific methods
    - Behavioral, play, social
    - Communication, technology
    - Executive functioning

Evidence-Based Practices in Behavioral Health  
Series Editor: Melissa K. Singh

Russell Lang  
Terry B. Hancock  
Melissa K. Singh  
Editors

Early Intervention for Young Children with Autism Spectrum Disorder

Springer



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59

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## Challenges for adolescents and young adults

- **Adolescence as a challenge!**
- **Medical care issues**
- **Behavioral/Psychiatric interventions**
- **Need for additional supports**
  - Adaptive skills
  - Social Skills
  - Communication
- **Challenges regarding**
  - Transition into puberty, then adulthood
    - Insurance, medical care, social and vocational supports

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60

## Adaptive skills

- **“Real Life” skills**
  - Central to adult independence and self-sufficiency and outcome
  - Good measures available (e.g., Vineland Adaptive Behavior Scale)
  - Issues of skill GENERALIZATION
    - Communication, daily living, social skills
    - Vocational/transport skills
      - Driving
    - Case Examples

## Communication Skills

- **Perception (correct) that the most absolute progress happens early on but...**
  - Even nonverbal adults can be helped to be more communicative
  - Importance of awareness of various methods
    - High tech (computers, assistive devices, iPhone)
    - Low tech (picture exchange, schedules, etc.)

## Social Skills

- **Various approaches used**
  - Peer, hybrid, adult instruction
  - MOST of research has been done with younger children
  - Very limited research with older individuals
    - Who often need it the most!
- **How significant is the social skills gap?**
  - Effect size social skills about .4
  - Eye tracking differences 3.8!



64

## Better approaches to social skills teaching

- **More focus in schools and adult programs**
- **Need for better research (and more research) in this population**
- **Limitations of what we know (and generalize) from work with younger children**
- **Importance of support for individuals at all levels**
- **Potential for linking to better metrics**
  - E.g. eye tracking



66

## Sexuality issues

- **Changes in body and increased sexual interest but limited ways of learning**
- **Importance for both sexes of**
  - Basic education (adapt to understanding)
  - Awareness of privacy issues/vulnerability
  - For more able students
    - What can and can't be discussed
    - What can and can't be done and WHERE
  - Range of resources available



67

## Mental health supports

- **Need for new models**
  - Use of services as needed
  - “long haul” vision
  - Life coaching model
    - Much more proactive/interactive
    - Homework, role play, etc.
    - Collaboration with other care providers
    - Limitations in insurance reimbursement/coverage



68

## Legal Issues: I

- **For more able students**
  - In Asperger's some reports of troubles with law
  - Our experience is that overreliance on rules → trouble (often too moralistic!)
- **For less able students**
  - Meltdowns and aggression combined with communication problems → difficulties (particularly in public settings)

## Legal Issues II

- **Need for police and emergency personnel training**
  - Good models for doing this
  - Need for basic information
    - What is autism
    - How to approach
    - What to do and NOT do
  - Some examples of problem situations

## Legal Issues III

- **Transitions in the law in US (school → post secondary) (IDEA → ADA)**
- **Health insurance issues**
- **Issues in terms of who is responsible**
  - Variations between states
  - Importance of planning
  - Common mistakes/missteps
    - Assumptions about guardianship
    - Assumptions about role of siblings
    - Simply giving \$ may not be so simple!

## Vocational Planning

- **More and more frequently adults with ASD entering work force**
  - Range of supports
    - Sheltered employment → supported employment → independence
  - Need to consider
    - Strengths and weaknesses
    - Interests and challenges
    - Examples

## Challenges for employment

- **Social and communication problems**
- **Executive function difficulties**
- **Great costs for rehabilitation services**
- **Although much interest in supported employment programs 16 papers from 2000-2010 related to work**
- **Jobs obtained tend to be unskilled, poorly paid and sometimes STRESSFULL**

## Employment

- **Even in adults with normal IQ there are higher rates of economic and social disadvantage (Brugha, et al. 2011)**
- **Limited data**
  - Howlin & Moss(2012) only 33% in school or work
  - Issues re: use of services designed for ID
  - Job issues: stress and fit
  - Small number of papers available

## Living Arrangements & Relationships

- **Living - Range of possibilities**

- Group home → supported living → independent living
- Pros/cons of residential programs
- Integration of day and residential settings
- Transitional programs available

- **Relationships**

- Some friendships (10-20%)
- Some marry (3-20%)(limited info)
  - NO info on children



75

## Colleges grew out of monasteries!

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



76

## College and Vocational Schools

- **More and more students**
  - New challenges for supports
  - College is NOT a right in US
    - ADA and supports, self-identification
  - Use of peers/therapists
  - Academic vs. nonacademic challenges
  - Adaptive skills can loom large
  - Pros/cons of various alternatives
  - A range of transitional programs now available



77

## Needs in Research and Service

- **Emphasis on Evidence based treatments**
- **Translating results from research studies into practical applications**
- **Research needs**
  - Particularly in intervention
- **Service**
  - Evaluation of models of care
- **Public policy**
  - Dissemination of information to parents, schools, public, and students



78

## The importance of planning

- **Range of options available**
- **Having 'the vision thing'**
  - In general we want to encourage adult self-sufficiency, independence, & life satisfaction
- **Importance of a realistic assessment**
  - NOT just of academic (IQ, achievement)
  - BUT functional, social, vocational
- **Various paths to adult independence and support**



81

## Medical issues

- **Provider issues**
  - Insurance coverage
    - Often choices limited, ? Role of health care reform and new mandates
  - Medical care providers
    - Transition from pediatrician to adult based care
  - Psychiatric care issues
    - Role of child and adult psychiatrists
  - Need for new models of care



83

## Behavioral/Psychiatric Issues

- **Some (limited) number of medications officially FDA approved for autism**
- **“Off Label” use if quite frequent**
- **Some suggestion of potential differences in responsiveness, e.g., pre/post puberty**
- **Sometimes side effects of medication can be problematic**
- **Limitations of available research but more controlled studies available!**
  - Risperidone has clear benefit



85

## Mental Health

- **Background: Diagnostic overshadowing**
- **Rates**
  - Higher in case series (80%) and lower in more epidemiological samples (25-30%)
  - Many issues in diagnosis & assessment
  - Lack of good measures
- **Most common problems**
  - Lainhart (1999)
    - Anxiety: 4% - 58%
    - Depression: 7% - 84%
- **LIFE STRESSES!**



86

## Mental health supports

- **Most have no access to specialist intervention**
- **High rates of medical use (including those with higher IQ)**
  - Essenes et al. 2009
    - 88% on one medicine
    - 40% on 3 or more

## Case example

- **Please take a guess as to what the next page of equations is about!**



Can you guess this man's special interest?



Can you guess this man's special interest?



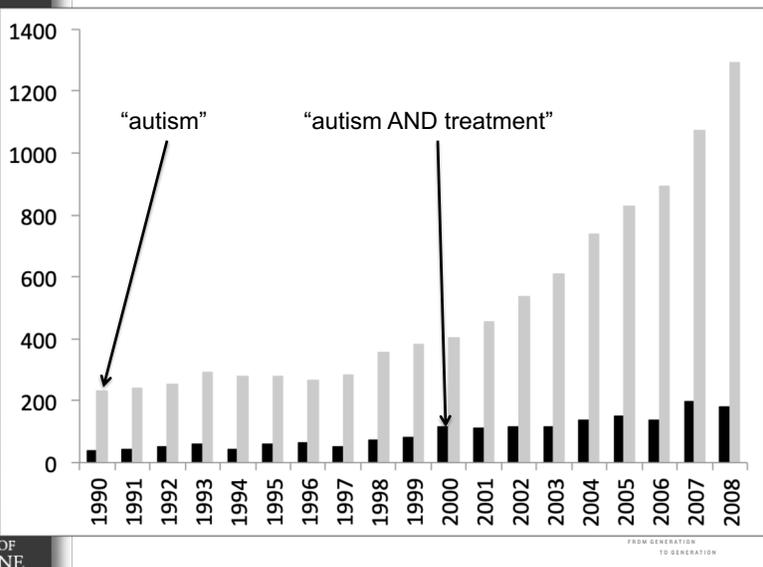


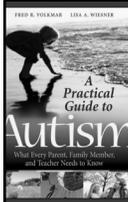
# Where are the gaps currently

- **Intervention research**
  - Particularly for older individuals
  - Very limited work on aging but apparently considerable need
- **Evidence base for treatments is quite variable**
- **Need for better metrics**
- **Subtyping and BAP**
- **New approaches to early diagnosis**



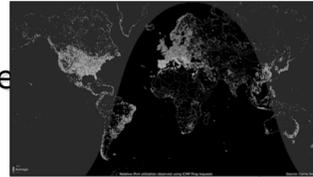
# Published Research in Autism (psycINFO)





## Social Policy issues

- **Little work on the 50 state wide experiments!**
  - **Translating results from research studies into practical applications**
  - **Challenges of getting quality info to parents**
    - As of last week type autism into Google:
      - >25,000,000 hits
    - We have online course
- Internet use over 24 hours →



97

## A quick story to (nearly)end!

- **Undergrad class**
  - 30 years (about 1000 students)
  - Various co-teachers
  - Format
    - Lecture
    - Experience
  - Lectures now on web
    - Featured on iTunes
    - >200,000s view on line!
  - Quick story (testament to progress in the field!)



99

# Thanks!



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102