The Changing Face of Autism:
A Developmental Perspective

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Growing up with Autism

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www.Childstudycenter.yale.edu or
http://www2.southernct.edu/academics/schools/education/autism-center/contact.html

Conflicts of Interest

- NIMH Grant HP50 MH115716
Welcome to 2018!

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
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

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!
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
Diagnosis and Epidemiology

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

- 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!)

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What happens to cases?

From NY Times

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From McPartland et al. JAACAP 51:368-383, 2012
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

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

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

- Single gene, Mendelian
- Cytogenetic
- "Common autism" (multiple genes, environment)
- Genome-wide Arrays
- 15q mat dup
- 22q11 del
- 2q tel del
- 22q tel del

~8% diagnostic yield in ASD at EGL

Genetics.emory.edu
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!
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

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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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**
ERPs and faces: Autism

Face Discrimination


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
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
**Group Results**

<table>
<thead>
<tr>
<th></th>
<th>Autism Group</th>
<th>Normal Controls</th>
<th>t values</th>
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<tbody>
<tr>
<td>mouth</td>
<td>41.2 (14.87)</td>
<td>21.18 (12.12)</td>
<td>4.026, p &lt; .000</td>
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<td>24.63 (8.07)</td>
<td>65.44 (12.78)</td>
<td>-10.455, p &lt; .000</td>
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<td>9.65 (5.14)</td>
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<td>object</td>
<td>9.58 (6.44)</td>
<td>3.71 (2.44)</td>
<td>3.286, p &lt; .003</td>
</tr>
</tbody>
</table>

Effect size (eyes): $d = 3.81$


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**What Does all this mean for outcome?!**

- **Development of effective evidence based treatments**
  - A range of kinds, programs, & methods

- **Increased awareness $\rightarrow$ earlier diagnosis $\rightarrow$ 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
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?**

Limitations of available research

- **Paucity of research available**
  - 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
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

Autism Interventions II

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

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!
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

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
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)

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

Colleges grew out of monasteries!

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

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
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

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
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!**
Legal Issues and Bullying!

- **Arise in various contexts**
  - Guardianship, involvement in criminal justice, long term estate planning
  - Increased risk (7X) involvement in criminal justice system
    - Poor judgment, social isolation, etc. increase risk
  - Asperger’s – case reports of violence
  - BUT. Not good systematic data

- **Bullying**
  - 40% if only ASD
  - 75% if ASD + something else
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**

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**Published Research in Autism (psycINFO)**

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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

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!)
References I:

References II: