THE CHANGING FACE OF AUTISM: A DEVELOPMENTAL PERSPECTIVE

FRED R. VOLKMAR MD
IRVING B. HARRIS PROFESSOR – CHILD STUDY CENTER, YALE UNIVERSITY
DOROTHY GOODWIN CHAIR OF SPECIAL EDUCATION – SOUTHERN CONNECTICUT STATE UNIVERSITY
EDITOR: JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS

CONFLICTS OF INTEREST

OVERVIEW

• SOME GOOD AND SOME LESS GOOD NEWS
• OVERVIEW OF OUTCOME IN AUTISM
  • IN RELATION TO VARIOUS ISSUES
• DEVELOPMENTAL IN SEVERAL SENSES
  • 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

WELCOME TO 2020!
GENERAL PRINCIPLES:
- The interaction of research with clinical work:
  - Feb. Blizzard
  - My patient's text

ORIGINS OF INTEREST
- Case reports in 1800's
- Itard, US reports, European reports
- Major landmarks
  - Kanner (1943) "Early Infantile Autism"
  - Asperger (1944) "Autistic Personality Disorder"
  - Commonality was the Autism (complicates understanding social interaction)
- Features: Autism (social), communication, unusual behaviors
- Official recognition (1980)
  - Explosion of research

WHAT IS IN A NAME?
- Άυτός
  - The intended sense of Άυτός 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
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 (90-95%) scored <70 overall

- False impression of high parent SES
- In fact higher rates of social problems

- 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
    - Broad autism phenotype (BAP)

- DSM-III (1980)
  - First inclusion!
  - Infantile autism/residual autism
  - Atypical category

- DSM-III-R (1987)
  - DSM-IV / ICD-10
    - 12 criteria grouped in 3 areas: social/communication, play/behaviour
    - Polythetic (total of 12, at least 3 social/communication)
    - Includes Asperger's and atypical autism as subcategories

- DSM-5
  - 12 criteria: social/communication & behaviour, 12 possible combinations
  - No Asperger's, no atypical autism
  - NEW: SCD - social/communication disorders: communication disorder

DSM-5 ASD

- ASD + SCD
- No subtypes/subthreshold
- New for ASD severity dimensions
  - Criteria:
    - Two rather than three categories
    - Quantitative in nature
    - Vastly reduced criteria set
    - More broad (from 12 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)


• REANALYSIS DATA FROM 933 CASES IN DSM-IV FIELD TRIAL
  • ASP GUILINN D/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
  • WT ASD AUTISM = .76, ASP = .25, PDD-NOS = .28
  • IQ <70 SE = .70, >70 = .46

CURRENT STATUS OF NOSOLOGY

• GOOD NEWS
  • GOOD DIAGNOSTIC ASSESSMENT INSTRUMENTS
  • BETTER AWARENESS
  • BETTER SERVICES
  • INCREASED GLOBAL INTEREST

• BAD NEWS
  • OUR SCREENERS DO NOT WORK SO WELL FOR YOUNG CHILDREN
  • DSM-5 DOESN'T WORK WELL FOR MORE COGNITIVELY ABLE
  • ASPERGER'S DISORDER LEFT HANGING
  • BROADER SPECTRUM LEFT HANGING

RESEARCH PROGRESS: GENETICS

• FIRST TWIN STUDY IN LATE 1970S
• VAST INCREASE IN WORK
• MANY GENES INVOLVED
• BROAD SPECTRUM NOTION SUPPORTED
• MANY OF THE 50+ GENES FOUND INVOLVE NERVE-NERVE CONNECTIONS IN THE BRAIN
RESEARCH PROGRESS: EDUCATION

- Influential NRC Report 2001
- Reviews 10 programs with some evidence both
- Many commonalities and some differences
- Structured teaching important
- At least 25 hours a week!
- Much more work on treatment
- Evidence based research
- Types and quality of evidence
- Model programs
- Behavioral
- Developmental
- Hybrid
- Eclectic
- Specific interventions
- ABA, social skills, PECS, etc.

RESEARCH PROGRESS: NEUROSCIENCE

- A range of methods used
- Importance of understanding the social brain - Autism is a model!
- Various methods - fMRI, EEG, eye tracking
- Findings help us understand the contribution of brain functions to Autism

ONE EXAMPLE: LOOKING AT RACES 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

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

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

McPartland, Dawson, Webb, Panagiotides & Carver, 2004
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
- finding now replicated >20 times

Face Recognition:
Fusiform Gyrus Group Differences

DIFFERENCES IN OBJECT "SALIENCY" – FALLING IN LOVE WITH DIGIMON

"Digimon" (Digital Monsters)

Greater Interest/Attention to Digimon than People

Courtesy of Robert T. Schultz, Ph.D. and David Greleoti, MD

Greleoti et al., 2005, Neuropsychological
META-ANALYSES

• Clements ET AL, EVALUATION OF THE SOCIAL MOTIVATION HYPOTHESIS OF AUTISM
  - JAMA Psychiatry. 2018;75(8):797-808. DOI:10.1001/JAMAPSYCHIATRY.2018.1100
  - “IN THIS META-ANALYSIS OF 12 FUNCTIONAL MAGNETIC RESONANCE IMAGING
    STUDIES, 239 PARTICIPANTS WITH AUTISM SPECTRUM DISORDER SHOWED ABERRANT
    REWARD CIRCUITY ACTIVATION TO BOTH SOCIAL AND NONSOCIAL REWARDS AND
    INCREASED ACTIVATION TO STIMULI ASSOCIATED WITH THEIR RESTRICTED INTEREST.
    MEANING AUTISM SPECTRUM DISORDER MAY ARISE FROM AN EARLY
    NEUROBIOLOGICAL DIFFERENCE IN RESPONSE TO REWARDING SOCIAL INPUT, WHICH
    IN TURN MAY LEAD TO DIMINISHED SOCIAL MOTIVATION, ABERRANT PROCESSING OF
    REWARDS EXTENDS TO NONSOCIAL STIMULI AND MIGHT UNDERLY INCREASED
    MOTIVATION FOR RESTRICTED INTERESTS.”

EYE TRACKING RESEARCH

• ECOLOGICAL VALIDITY
  - MOVE PAST USE OF STILL PHOTOS!
  - 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

Typical Viewer
Age: 27, FSIQ: 110

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

META-ANALYSES EYE TRACKING

- CHETA-TEJARK M. 2016: RES. DEV. DIS. 48:75-93
  - Individuals with ASD spend less time attending to social stimuli than controls ($d = 0.55$).
  - Social attention in ASD was most impacted when stimuli had a high social content.

- PAPAGIANNOPOULOS ET AL. J. SOC. NEUROSC. 9: 610-633, 14 STUDIES
  - Significant attention eye mouth more variables.
  - HTTPS://DOI.ORG/10.1080/17470919.2014.934966

- HAO ET (2018): AADV. PSYCHOL. SCIENCE. 26:24-34, 43 STUDIES $>13100 SS$
  - Very strong differences eye fixation ($d = -0.75$).
  - HTTP://JOURNAL.PSYCH.AC.CN/XLKXJZ/EN/Y2018/V26/I1/26

PUTTING IT ALL TOGETHER – PSYCHOLOGICAL MODELS OF AUTISM

- THEORY OF MIND
- CENTRAL COHERENCE
- EXECUTIVE FUNCTIONING
- ENACTIVE MIND

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!

WHAT IS THE SITUATION IN AUTISM? – IT IS AS IF PEOPLE ARE HIDDEN! CAN YOU FIND AND COUNT THE NAVY SEALS?
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AS WE IMPLEMENT BETTER INTERVENTIONS WE SEE BETTER OUTCOME!

ISSUES

- PUBLIC LAW 94-142
- EVIDENCE BASED TEACHING INFORMED BY RESEARCH
- OUTCOME RESEARCH
  - GOOD
  - FAIR
  - PAIR

UNDERSTANDING OUTCOME

- OPTIMAL OUTCOME
  - WHAT IS THIS?
  - HOW OFTEN DO YOU SEE IT AND WHERE?
- CHALLENGES FOR PREDICTION
  - NOTE VERY LITTLE ON NEEDS OF OLDER ADULTS (PAST YOUNG ADULTHOOD)
  - ALSO NEED TO TAKE INTO ACCOUNT THE WISHES OF THOSE WITH ASD

OUTCOME STUDIES TWO SNAPSHOTS

GOOD NEWS!

- OVERALL OUTCOME IS IMPROVING
  - 1980
  - ABOUT 90% OF ADULTS IN 24/7 CARE
  - ABOUT 75% NEVER TALKED
  - FEW WENT TO COLLEGE OR WERE EMPLOYED

- NOW (2014)
  - ABOUT 25% LIVING INDEPENDENTLY,
  - <20% REMAIN MUTE
  - MANY GOING TO COLLEGE
  - MANY SEEKING EMPLOYMENT

- WHY IS OUTCOME BETTER
  - EARLY DIAGNOSIS
  - EARLIER INTERVENTION
  - A RANGE OF EVIDENCE-BASED PROGRAMS AND INTERVENTIONS
  - MORE INCLUSION AND FOCUS ON SOCIAL SKILLS

- WHERE IS THE BEST PLACE TO LIVE

41
42
43
44

4/10/20
4/10/20

**UTAH !!!!!!!**

- 41 INDIVIDUALS WITH AUTISM (MEAN AGE 31 YEARS)
  - OUTCOME DATA
    - MEAN IQ 89
    - INDEPENDENT: 48%
    - SEMI-INDEPENDENT: 33%
    - EMPLOYED: 66%
    - LONG TERM RELATIONSHIP: 20%
    - NOTE GEOGRAPHIC LOCATION
    - ALSO LIMITATIONS OF EARLY PRODUCTIONS

**ECONOMIC ISSUES!**

- COST OF AUTISM FOR ADULTS CAN BE HIGH
  - GANZ (2006)
    - IN US CAN BE $1.2 MILLION (LIFE TIME)
    - ABOUT $10 BILLION (MID) 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

**CHALLENGES: 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 WITH MEDICAL, PSYCHIATRIC, 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, MENTAL
  - VOCATIONAL/TRANSPORT SKILLS
  - DRIVING
- CASE EXAMPLES

**MORE CHALLENGES!**

- SOCIAL COMMUNICATION SKILLS
  - VARIOUS APPROACHES USED
    - PEER, HYBRID, ADULT INSTRUCTION
  - MOST OF RESEARCH HAS BEEN DONE WITH YOUNGER CHILDREN
    - HARDLY ANY 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
      - 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
          - AWKWARDNESS
          - FOR MORE ABLE STUDENTS
          - WHAT CAN AND CAN'T BE DISCUSSED
          - WHAT CAN AND CAN'T BE DONE AND SHARED
      - RANGE OF RESOURCES AVAILABLE
OTHER ISSUES

• MENTAL HEALTH PROBLEMS
• COMORBIDITIES
  • ADOLESCENTS – ANXIETY, DEPRESSION
  • HIGH RATES OF SUICIDAL THINKING
  • SUBSTANCE ABUSE PROBLEMS
  • MAY SELF-MEDICATE ANXIETY, DEPRESSION
  • GENDER IDENTITY ISSUES
  • GIVEN THAT FUNDAMENTAL SOCIAL PROBLEMS THIS IS NOT SURPRISING

• LEGAL ISSUES – 7X INCREASED RISK
  • FOR MORE ABLE STUDENTS
  • IN AGENDA’S SOME REPORTS OF TROUBLES WITH LAW
  • OUR EXPERIENCE IS THAT OVERRELIANCE ON RULES (TROUBLE OFTEN TOO MORALISTIC)
  • FOR LESS ABLE STUDENTS
  • MISDIAGNOSES AND AGGRESSION
  • COMBINED WITH COMMUNICATION PROBLEMS – DIFFICULTIES (PARTICIALLY IN PUBLIC SETTINGS)

EMPLOYMENT

• WORK STUDENTS WITH ASD GOING TO WORK
• CHALLENGES
  • SOCIAL AND COMMUNICATION PROBLEMS
  • EXECUTIVE FUNCTION DIFFICULTIES
  • GREATER COST FOR REHABILITATION SERVICES
  • ALTHOUGH MUCH INTEREST IN SUPPORTED EMPLOYMENT PROGRAMS VS COLLEGE
  • ODD ISSUES RELATED TO WORK
  • ISSUES RE: USE OF SERVICES DESIGNED FOR ID
  • EDIT ISSUES: STRESS AND FIT
  • SMALL NUMBER OF PAPERS AVAILABLE

• EVEN IN ADULTS WITH NORMAL IQ THERE ARE HIGHER RATES OF ECONOMIC AND SOCIAL DISADVANTAGE

EMPLOYMENT CONTINUED

• ABOUT HAlF OF ADULTS UNEMPLOYED
• UP TO 1/3RD OF COLLEGE DEGREES MAY BE UNEMPLOYED OR UNDER EMPLOYED
• COMPLEXITIES FOR THE LESS COGNITIVELY ABLE
• LIMITED OPPORTUNITIES, EARN BELOW MINIMUM WAGE
• GOOD NEWS
  • EMPLOYERS OFTEN REPORT – STRENGTHS FOR MEMORY IN DETAIL, ABILITY TO FOLLOW RULES AND PROCEDURES
  • INCREASE NUMBER OF PROGRAMS AVAILABLE

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

4/10/20
**COLLEGE AND VOCATIONAL TRAINING**

- Good News:
  - Colleges grew out of monasteries
  - Order, routines, structure
  - Many things readily available
  - Can (somewhat) minimize social interaction

- Great problems are:
  - Big transition from high school
  - Adaptive skills
  - Organizational skills
  - Need for personal independence
  - Use routines
  - Many things available
  - Food, books, entertainment
  - You can minimize social interaction!

- More and more students
  - New challenges for supports
  - 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

**CHALLENGES FOR COLLEGE**

- Their usual accommodations (ADA)
  - Extra time, tutors, all ok but
  - Need for help with a host of areas
  - Executive function
  - Social interaction – peers
  - Ruling
  - Self-care, adaptive skills

- Transition programs
  - >70 around US – limited data
  - Vary in format and organization
  - S. White program at Alabama
  - TEACCH program
  - SCSU developing program
  - Interface with Chapel Haven

**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)
  - Limited on gender/ethnic/age data

**CASE EXAMPLE**

- Please take a guess as to what the next page of equations is about!
NEEDS IN RESEARCH AND SERVICE

• Emphasis on evidence based treatments
• Translating results from research studies into practical applications
• Research needs
  • Particularly in intervention
  • Program evaluation – What works?
• Service
  • Evaluation of models of care
• Public policy
  • Dissemination of information to parents, schools, public, and students

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
  • >200,000 view online!
• Quick story (testament to progress in the field)

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