A HISTORY OF AUTISM
Dr. Scott Standifer
November 22, 2011

Disability Policy & Studies, University of Missouri

HISTORY OF AUTISM
SCOTT STANDIFER

Disability Policy & Studies
Region 7 TACE (Technical Assistance & Continuing Education) – Formerly RCEP 7
Supporting State Voc Rehab Agencies in MO, IA, NE, KS

Primary Author, online Adult Autism & Employment: a guide for rehabilitation professionals

HISTORY OF AUTISM
AGENDA

Session 1 – Short History
First Descriptions of Autism
- Leo Kanner
- Hans Asperger
- Bruno Bettelheim

Second Generation of Autism
- Sibyl Elgar
- Bernie Rimland – Autism Society DAN!
- Eric Schopler – TEACHH
- Lovaas – ABA
- Lorna Wing
**AGENDA**

- Session 1 – Short History, Continued
  - New Advocates
    - Temple Grandin
    - Autism Network International
    - Autism Speaks
  - The Great Wave
    - IDEA Data
    - CDC Data
    - RSA Data

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**FIRST DESCRIPTIONS**

1943 – mid-1960s

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**LEO KANNER**

- 1943 – defined autism
  - "Autistic Disturbances of Affective Contact"
  - Running child psychiatric clinic at John's Hopkins University
  - Described 11 children with similar features

- Kanner's original description
  - Lack of affective contact
  - Anxious obsession with sameness in environment & routine
  - Fascination with objects
  - Mutism or a "private" language

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**LEO KANNER**

- Term *Autism* borrowed from descriptions of schizophrenia
- Called condition "Early Infantile Autism" to distinguish it from schizophrenia
  - Emphasized autism not progressive

- Freudian Theory
  - Schizophrenia believed caused by parents
  - Kanner discussed possibility for autism
    - Noted mothers seemed cold, unemotional
    - Coined the term "Refrigerator Mother"
  - Seemed to have mixed opinion on causes
**Hans Asperger**

- Working at University of Vienna’s children’s clinic
- The year after Kanner, described group of 4 children
- Called the condition “Autistic Psychopathology”

**Features**

- Language disturbances – delayed language, odd use of pronouns, tend to lecture/discourse
- Difficulty in two-way conversations & social signals
- Clumsy movements and gestures, often not matching conversation
- Fixation and skill in one or two topics
- Often very smart

**Work overlooked until 1979**

- Published in German
- Not convincing explanation
- German established language of science
- New Theory
  - Adam Feinstein, *A History of Autism*
- Nazi Influence
  - Austria under Nazi rule, Nazi’s eliminating “defective” people
  - Asperger used “Nazi-friendly” language in description of children/condition
  - Outside readers would dismiss as Nazi sympathizer

**Bruno Bettelheim**

- Director of child psychiatric clinic at University of Chicago
  - Brought public awareness of autism
    - Series of magazine articles starting in 1959
    - 1967 published *The Empty Fortress*
    - International best-seller
  - Advocate of Freudian Theory
    - Strong advocate of refrigerator mother theory
    - Treatment required pulling children out of family situation “causing” the autism
    - Profiles 4 cases of “cured” children
  - Refrigerator mother theory may be self reflection

**Survivor of Nazi Concentration Camp**

- Two schools of thought on impact
  - Supporters – empathized with children as survivors of family horrors
  - Camps tore down personalities, so he used same techniques to “rebuild” children
  - Detractors – re-enacting personal memories with children as victims
- Authoritarian approach to care of children with autism
  - Offensive to many in autism community, then and now
1969 Elvis Presley Movie
- Elvis is a doctor
- Mary Tyler Moore is a nun
- Elvis cures a young girl of autism by hugging her and saying he loves her

SECOND GENERATION
mid-1960s – mid-1980s

Sybil Elgar
- National Society for Autistic Children (UK) - 1962
  - Parent group in London
  - Promote awareness & services for children
- Sybil Elgar
  - Montessori trained
  - 1962 - began school for children with autism in her basement
  - Part of Autistic Society
  - 1965 - Formal school opened on Florence Road in West London
  - Foundation of education intervention movement in autism

Bernie Rimland
- San Diego-based psychologist with son diagnosed with autism in 1958
  - Appalled by Bettelheim
  - 1964 – published *Infantile Autism: The Syndrome and Its Implications*
    - First major assault on Bettelheim
  - 1965 – Co-founded National Society for Autistic Children (now the Autism Society of America)
**Bernie Rimland**
- In 1980s became focused on biological treatments for autism
- 1995 – Founded Defeat Autism Now! (DAN)
  - Part of Rimland's Autism Research Institute (ARI)
  - Medical researchers investigating "alternative" therapies
    - Special Diets (allergies)
    - Chelation (extraction of heavy metals)
    - Supplements
  - Suggest autism may be a host of disorders with common outcomes, not one disorder
- Early proponent of vaccine theory

**Eric Schopler**
- 1972 founded TEACCH
  - Treatment and Education of Autistic and Communication related handicapped Children
  - Elaborated much of Sybil Elgar's approach, but in a research setting
- A major force in autism education
  - TEACCH Approach
    - Understand impact of autism on each person
    - Focus on strengths
    - Address understanding and perception, not behavior.
      - Communicate "why"
    - Structure environmental supports, particularly visual supports, address sensory issues
    - Involve family members

**Ivar Lovaas**
- Research with children at UCLA, early 1960s
- Applied Behaviorist (Skinner) techniques to autism
- System of both rewards and punishments
  - Punishments drawn from techniques of mental institutions
  - 1965 Life Magazine photo essay, "Screams, Slaps, & Love" captured darker side of techniques
- Lovaas later developed milder techniques
  - Harsh ones were "best we had"
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IVAR LOVAAS

- Adapted Applied Behavior Analysis to autism treatment
  - Called ABA, Lovaas Technique, or Intensive Behavioral Intervention
- A major feature of autism intervention
- Differences from TEACCH
  - ABA focused on behavior, not cognition
  - ABA focused on achieving "normalcy" and replacing problem behaviors with acceptable ones
  - Lovaas Technique VERY time intensive
- Similarities with TEACCH
  - In practice, both draw from the other when developing specific interventions—whatever works

LORNA WING

- Co-founder of National Autistic Society, mother of child with autism
- Researcher at Maudsley Hospital in London in 1960s & 1970s
- 1970s - Set out to validate Kanner's description by surveying children with disabilities in Camberwell
- Used three core features for functional definition
  - Found Kanner accurate for some, but not broad enough for others
  - Suggested a "continuum", later "autism spectrum"
- "Triad" features became part of DSM criteria in 1987

NEW ADVOCATES

mid-1980s – today
NEW ADVOCATES

- Mid 1980s, ASA Co-founder Ruth Sullivan on the way to ASA conference in Chicago
- Met Temple Grandin
  - Asked to present at next ASA conference

TEMPLE GRANDIN

- Grew up in New Hampshire in 1960s
- Received something like Lovaas technique
- Attended college, earning PhD in Animal Science
- Teaches at Colorado State Univ.
- Designs livestock facilities
- After ASA conference, became speaker
- Published first book in 1986
- Featured in Oliver Sacks’ book in 1995
- 2010 HBO Biographical Movie

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NEW ADVOCATES

- 1989- Movie Rain Man
  - Sympathetic view
  - Based on real individuals
  - Individualistic communication issues were well depicted
  - Some false impressions

AUTISM NETWORK INTERNATIONAL

- Late 1980s, people with autism attending autism conferences as a way to meet each other
  - Not autism friendly environments
- 3 adults with autism - Jim Sinclair, Donna Williams, Kathy Lissner - met in St. Louis for 3-day visit
  - Sinclair – “I had met someone who came from the same planet as me”
- Started Autism Network International
  - 1992 – first newsletter
  - Sinclair promoted on internet
  - 1993 - “Don’t Mourn For Us” (Sinclair), directly challenging the “autism as tragedy” image
  - 1994 – list serve for people with autism
**HISTORY OF AUTISM**

**AUTISM NETWORK INTERNATIONAL**
- Beginning of autism self advocacy and peer mentoring
- Two new concepts:
  - Neurodiversity – differences in brain function are part of normal human diversity, not something to be cured
  - Neurotypical – good-natured term for people who do not have autism

**AUTISM SPEAKS**
- Bob & Suzanne Wright founded in 2005
  - Grandson diagnosed with autism
  - Bob former Vice Chair of GE
- Sponsors autism research
  - Strong focus on causes and biomedical cure
  - Conducts awareness and outreach activities aimed at the public and governments
- Within 3 years had merged/absorbed three other advocacy groups

**CONFLICT AMONG NEW ADVOCATES**

**AUTISM SPEAKS & Neurodiversity Movement**
- Often hostile to each other
  - Autism Speaks emphasizes cures/treatments and often portrays autism as a "tragedy" in publicity / fund raising campaign
  - Neurodiversity movement feels people with autism should be respected & supported for who they are, not viewed as tragedies to be fixed
THE GREAT WAVE
late-1990s – today

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THE GREAT WAVE
- 1975 - Education For All Handicapped Children Act (EHA)
  - Beginning of Special Education
  - Did not list specific qualifying disabilities
    - Autism diagnosis still in limbo, medically
- 1990 - Individuals with Disabilities Education Act (IDEA)
  - Update of EHA and revisions
  - Now listed 9 specific disabilities, including autism
  - U.S. Dept of Ed began collecting incidence data for each disability
  - No previous hard data on autism in U.S.

THE GREAT WAVE
- Early 2000, media attention to dramatic rise in Autism prevalence in the United States among children 6 to 21 years of age, 1993 – 2003
  - From US Dept. of Education data – 22,000 to 140,000
  - Approximately 650% increase (some sources say 800% +)
    - Chart from Leader, J. L. Pediatrics 2005

THE GREAT WAVE
- The rise has continued, now tracking 15 years
  - From US Dept. of Education data
  - 22,000 – 330,000
  - 1500% increase over 15 years

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Children with ASD, age 6-21

Children with ASD, age 6-21
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THE GREAT WAVE

- Or maybe not
  - Increases in autism matched by decreases in other categories
    - Diagnostic Substitution
      - Shattuck, P. 2006
  - Anomalies in the data suggest features of the school system and reporting system have a big impact on figures
    - Laidler, J. R. 2005

CDC Data – 2002 - on

- Measuring prevalence in 8 year old children
- 2002: 6.6 children with Autism per 1,000 on average
  - 1 in 151 children
    - drawn from 14 states/sites
    - Ranged from 3.3 to 10.6
- 2006: 9 per 1,000 on average
  - 1 in 111 children
    - drawn from 11 states/sites
    - Ranged from 4.2 to 12.1
      - Missouri among the highest
      - Some sites showed a decrease over this period

Prevalence Debate – is increase "real"?

- Prevalence of diagnosis versus "actual" prevalence
- Changes in diagnostic criteria
- Increased awareness among public and medical community
- For its tracking, CDC is accepting "diagnoses" from school staff in addition to medical professionals
  - Significant variation between states in CDC data
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THE GREAT WAVE

- Unpublished Data from Rehabilitation Services Administration
  - Nationally, the number of people with Autism applying for vocational rehabilitation services increased 300% from 2003 to 2008
  - Increase due entirely to transition students
  - 2003 is ten years after the beginning of Dept of Ed IDEA data

IDEA & RSA DATA COMPARISON

IDEA Data 1994 - 1999
- Original IDEA chart was 1994 – 2009. Enlarging IDEA data to compare similar time scales – the curves are very similar

IDEA Data 1994 - 2009
- Comparing to the 15-year IDEA data, there is reason to think RSA numbers will continue to climb

IDEA Data 2003 - 2008
- Ultimate, it does not matter
  - Definite, dramatic increase in the number of young people defined as having autism who will need adult services
END