When Autism and Deafness Coexist: Cultural Influence or Cultural Confusion?

GRI First Wednesday Research Seminar Series
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Special thanks to..

- Dr. Patrick Brice
- My classmates
- Jennifer Reesman
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- Faculty and Staff of the Psychology Department at Gallaudet
Concerns surrounding the apparent increase of Autism has soared in both research and publicity during the last 10 years. However, research often fails to examine cultural or linguistic differences of children who have Autism. More specifically studies which specifically look at children who are Deaf as well as have Autism are limited, almost nonexistent. Therefore, the following study was conducted to collect information related to the most common parent reported symptoms of Autism in children who are Deaf and have a previous diagnosis of Autism.
Pervasive Development Disorders

- Autistic Disorder
- Asperger’s Syndrome
- PDD-NOS
- Rett’s
- CDD

Autism Spectrum Disorders
Brief review of the Literature

- First introduced in 1943 by Leo Kanner as Early Infantile Autism (Johns Hopkins University)
- Kanner described what he noticed was Autistic thinking or Autism traits in children from birth
  - Peculiar and limited language, odd movements and behavior, lack of bonding with parents and preference to be alone
- Intelligence can be normal or impaired (Gillberg, 1988)
  - 70% will have IQ’s in the MR range
  - Splinter and Savant skills
- Today Autism is often diagnosed before age 3
  - Indicators of Autism as young as 1-year-old (Osterling and Dawson 1994)
- The best treatment for Autism is still unknown
- We currently cannot prevent Autism from happening
  - There is not yet a genetic or blood test to detect Autism
### Some Common Characteristics Seen in Persons With Autism

#### Challenges With Social Interactions:
- Challenges interpreting nonverbal language
- Difficulty with pretend play
- Rigid adherence to rules
- Poor eye gaze or avoidance of eye contact
- Few facial expressions and trouble understanding the facial expressions of others
- Poor judge of personal space – may stand too close to other students
- Trouble controlling emotions and anxieties
- Difficulty understanding another person’s perspective or how their own behavior affects others

#### Communication Challenges
- Often delayed in expressive and receptive language; may not speak at all
- Very literal understanding of speech; difficulty in picking up on nuances
- Echolalia – may repeat last words heard without regard for meaning
- Lack of pretend play

#### Behavior Differences
- Unusually intense or restricted interests in things (maps, dates, coins, numbers/statistics, train schedules)
- Unusual repetitive behavior, verbal as well as nonverbal (hand flapping, rocking)
- Unusual sensitivity to sensations – may be more or less than typical students
- Difficulty with transitions, need for sameness
- Possible aggressive, disruptive, or self-injurious behavior; unaware of possible dangers
Etiology

- “Refrigerator Mothers”
  - First used by Kanner and then Bettelheim
  - Psychological harm comes from mother
    - compared autism to the same likeness of being a prisoner in a concentration camp (the parents were hypothesized to be the guards) (Bettelheim, 1964)

- Genetics (Zimmerman, 2005)
  - 90% of monozygotic twins, 10% of dizygotic twins
  - Birth of one child with Autism, 9% increase for another

- Neurological
  - Abnormal Amygdala size or Cerebellum activity
  - Mirror Neurons (Ramachandran, 2000)
The MMR Vaccination Theory
- MMR vaccines contain thimerosal, a Mercury preservative added to childhood vaccines
  - MMR is given to 2-year-olds, often the time that Autism symptoms are often 1st noticed
  - The prevalence of Autism after the introduction of the MMR (1988) noticeably increased causing belief that MMR vaccines cause Autism
  - In 2001 thimerosal was removed from all vaccines for children by the Centers for Disease Control (Madsen, Lauritsen, and Pedersen, 2002)
- Despite removal of thimerosal in 2001, prevalence of Autism has continued to rise (Schechter and Grether, 2008)
- The MMR vaccine and thimerosal do NOT cause Autism
Culture and Autism

- Epidemiological studies have shown different rates of Autism in different countries despite same diagnostic criteria (Fombonne, 2003)

- Hispanic children are diagnosed less often than expected
  - States with the highest Hispanic populations have far smaller prevalence rates than expected (Arizona, New Mexico, and Texas)

- Hispanic Parents report different symptoms than expected (Overton, Fiedling, and Alba, 2007)
African American children less likely to get an Autism diagnosis on first visit when compared to white children, up to 1.5 years later (Mandell et al., 2007)

“Culture defines disability” (Grinker, 2007, p.11)

Some cultures do not have a word for autism, some cultures manifest autism differently

Cultural factors affect recognition and interpretation of symptoms by the clinician and parents and how the child presents making it possible for differences to occur cross culturally (Mandell et al., 2007)
Prevalence

- **1968**
  - 4 in 10,000

- **1980’s**
  - 1 in 10,000 children

- **Centers for Disease Control and Prevention (2001)**
  - 1 in 166 children

- **Centers for Disease Control and Prevention- (Feb 2007)**
  - 1 in 150 children (specifically 8-year-olds)

- **Annual Survey for Deaf and Hard of Hearing children and Youth 2004-2005 (GRI)**
  - 1 in 104 Deaf children
Sign Language and Autism

- Those with Autism, even severe, when taught sign-language improve
  - Improved behavior, spontaneous communication, toileting, self-injurious behaviors (Bonvillian, 1976, 1981, 2007; Carr, 1971) and social (Jure et al. 1991)

- “Language deficiency of [hearing] autistic children… due to an inability to make specific cross-modal associations, not just an inability to process auditory or visual information” (Fulwiler & Fouts, 1976, p. 44)

- The motor, kinesthetic, and visual systems in autistic children [hearing] are less impaired than the auditory-vocal systems (O’Conner, 1971)

- “These children [hearing] should be placed in a special class at a school for the deaf that provides not only sign language but also a program of behavioral management.” (Jure, et al, 1991,p 1070)
Autism and Deafness

- **Age of Diagnosis** (Mandell et al. 2005)
  - Hearing child with Autism - 3.1 years
  - Child who is Deaf and has Autism - 4.1 years
    - Has been shown to be up to 5 years later (8 years old)
- “Children with Autism look deaf”
  - Failure to respond to name, difficulty acquiring spoken language, social engagement differences
- Children with Autism are 10 times more likely to have hearing loss (Rosenhall, 1999)
- Congenital hearing loss is the most commonly reported coexisting condition of Autism (Zimmerman, 2005)
Autism and Deafness

- Educational challenges of deafness and autism (e.g., Malandraki and Okalidou, 2007)
- Sign language for deaf children with Autism has been shown to be beneficial (e.g., Fulwiler and Fouts, 1976 and Ruttenberg and Gordon, 1967)
- Only 1 study has ever studied the characteristics of children who are deaf and have Autism (Roper et al. 2003)
  - Concluded that Deaf and hearing children look the same
  - Sample of 9 teenagers, 17 years old using the ABC, minimal sign language
    - Did not explain etiology of deafness or parental hearing status
    - Concluded that deaf children can be diagnosed using the same measures as hearing children
Szymanski (2007)

- Autism Spectrum Disorders and Deafness Questionnaire (ASDDQ)
  - 51 Likert scaled questions (Always, Sometimes, Often, Never)
  - Demographic Information
    - Age of diagnosis of Autism as well as hearing loss, cause of hearing loss, parental hearing status, school placement, method of communication etc.
  - Four Different Scales
    - Behavior, Social, Communication, Family
    - Consisting of several common questions pertaining to Autism
      - Avoids eye contact, difficulty understanding facial expressions, Avoids physical contact, Engages in pretend play, Plays with others, Repetitive
Szymanski (2007)

- **Participants**
  - 16 total (5 PDD-NOS, 11 Autism)
    - 13 Deaf of Deaf, 3 Deaf of Hearing
    - Ages 2-years and a half to 13-years-old
    - All children were suspected to be deaf before age-2
      - Genetic causes N = 14, Meningitis N = 1, Unknown N = 1
  - Communication
    - ASL only N = 4
    - ASL, pictures, and gestures N = 5
    - Mixture of home signs, TC, ASL, pictures, gestures N = 7
  - Knowledge of ASL
    - More than 50 signs, N = 9
    - Between 26 and 50 signs, N = 3
    - Less than 25 signs, N = 4
### Szymanski (2007)

- Item means and scale means were used (M > 2.26 was considered characteristics consistent with Autism)

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Overall</th>
<th>Autism</th>
<th>PDD-NOS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>2.44</td>
<td>2.36</td>
<td>2.60</td>
</tr>
<tr>
<td>Social</td>
<td>2.61</td>
<td>2.62</td>
<td>2.60</td>
</tr>
<tr>
<td>Communication*</td>
<td>2.13</td>
<td>2.13</td>
<td>2.11</td>
</tr>
<tr>
<td>Behavior*</td>
<td>1.85</td>
<td>1.96</td>
<td>1.61</td>
</tr>
</tbody>
</table>

Note. The higher the score the greater the impairment for that scale, 0-4. Significant difference from the expected mean 2.25 was found for all scales except Communication.
Parents did report their deaf child...  

<table>
<thead>
<tr>
<th>Social</th>
<th>Family</th>
<th>Communication</th>
<th>Behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>• avoids interacting with peers</td>
<td>• has difficulties expressing needs or desires</td>
<td>• is not good at turn taking in conversations</td>
<td>• does not correctly use facial expressions</td>
</tr>
<tr>
<td>• has difficulties understanding deaf culture</td>
<td>• does not use age appropriate sign language</td>
<td>• Makes normal eye-contact when signing or talking</td>
<td>• facial expressions do not match actions</td>
</tr>
<tr>
<td>• Ritualistic</td>
<td>• cannot sustain 2 way conversations</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. On the ASDDQ these items had M > 2.25  

Szymanski, 2007
Parents did not report their deaf child...

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<tr>
<td>• looks through people</td>
<td>• Gestures in an odd way</td>
<td>• Echolalia</td>
<td>• Stares at hand or objects for more than 5 seconds</td>
</tr>
<tr>
<td>• laughs giggles or cries inappropriately</td>
<td>• Repeats signs or phrases (echolalia)</td>
<td>• Repeats odd phrases</td>
<td>• Inappropriately flaps, spins or rocks</td>
</tr>
<tr>
<td></td>
<td>• exaggerates signs</td>
<td>• Difficulty with sign production</td>
<td>• Slap hit or bite themselves</td>
</tr>
<tr>
<td></td>
<td>• Self-stimulates</td>
<td>• Inappropriately answers questions</td>
<td>• difficulty understanding facial expressions</td>
</tr>
</tbody>
</table>

Note. On the ASDDQ, these items had M < 2.25
- **School placement**
  - Children in residential schools ($n = 10$) had better overall results than children in public schools ($n = 5$), ($t (13) = -2.683, p = .019$)
  *communication scores did not differ, 1 child was not included*

- **Knowledge of sign language**
  - Children who knew more than 50 signs ($n = 9$) had better overall results than those who knew less than 50 signs ($n = 7$), ($t (14) = 2.35, p = .034$)

- **PDD-NOS vs. Autism**
  - Chi square tests were run to determine if the scores of the children matched the expected diagnosis (PDD-NOS, $M < 2.25$, Autism, $M >2.25$) for all scales. Results indicate that children did not score as expected.

- Of the 16 totally participants only 6 met all of the criteria needed to diagnose Autism
Conclusions

- Parents did not report the same characteristics as are often reported in children who have Autism
  - Family and Social scales were reported to be most impaired, while Communication and Behavior were reported as less of a problem

- Knowledge of sign language significantly improved scores

- Deaf children with Autism are being diagnosed without interpreters, without professionals who have knowledge of deafness and Autism, schools often are unsure of services for the child
Conclusions (cont’d)

- Differences between parental hearing status
  - Does early sign language exposure cause Autism to develop differently?

- Is there a cultural component happening?
  - “Culture defines disability” Grinker, 2007, p.11
  - Does Autism look different in these children because it is different? Can we even call this Autism if it doesn’t meet the criteria?

- More research is needed