Demystifying Disproportionality in Autism Identification: Prevalence, Policy, and Best Practice

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Agenda

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<th>Learner Objectives</th>
</tr>
</thead>
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<td>Part 1 – Amanda Sullivan</td>
<td>What does disproportionality mean in the context of autism?</td>
<td>Describe patterns and disparities</td>
</tr>
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<td>Part 2 – Tara Kulkarni &amp; Mollie Weeks</td>
<td>What is the role of IDEA? What can we glean from case law?</td>
<td>Understand policy dimensions</td>
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<td>Part 3 – Bryn Harris</td>
<td>What are the roles of language and culture? What are the limitations of current practice? What practices should we promote?</td>
<td>Identify principles of culturally and linguistically appropriate assessment</td>
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</table>
Amanda L. Sullivan, PhD, University of Minnesota

**Autism & Disproportionality**

“*The same program that can separate disadvantaged students from their peers, distinguish them with a stigmatizing label, and subject them to a curriculum or low expectations can also provide additional resources, supports, and services without which they cannot benefit from education...*”

Donovan & Cross, 2002, p. 20
What Is “Disproportionality”? 

- **Group differences** in identification, placement, or other outcomes
  - Differences in **individual's risk** due to sociodemographic group membership
- Common indices: risk, relative risk, composition

Disproportionality in Context 

**Disproportionality is inseparable from other educational outcomes and inequities**


Are We Identifying the Right Students?

What is disability?

Do we reliably identify disability?

How do we account for environmental determinants?

Are educational decisions unbiased?

… We’re not sure.

Reliability & Bias in School-based Evaluation

- clinicians frequently have difficulty differentiating ASD from other disorders, particularly for CLD youth
- racial/ethnic minority children who meet diagnostic criteria tend to be identified later in school
- school psychologists may be prone to under-refer and under-identify students who present with characteristics of autism
  - Detection of bias complicated by lack of data-based decisions and general unreliability
Challenges to School-based Identification

\[ \sim 25\% \]
of evaluators use best practices in autism identification.

School-based policy, procedures, and practices are malleable targets for outreach, policy refinement, and professional learning.

Describing Disproportionality Is Complicated

Disproportionality is a ‘multi-determined’ phenomenon.

Patterns of disproportionality vary by disability, level of aggregation, and unit of analysis.

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### ASD: CDC v. Special Ed

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<th>Race/Ethnic Group</th>
<th>Clinical Diagnosis</th>
<th>Educational Diagnosis</th>
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<tr>
<td>Proportion of Total</td>
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<tr>
<td>Prevalence Among Group</td>
<td>1 in 63</td>
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<td>Frequency</td>
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<td><em>Asian American</em></td>
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<tr>
<td>Proportion of Total</td>
<td>5.30%*</td>
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<td>Proportion of Total</td>
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<td>Proportion of Total</td>
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### Relative Risk Varies by State

Figure 1. Racial minority groups’ relative risk of school-based autism identification varied substantially by state in 2008–2009. The relative risk ratio is a ratio of the prevalence for the minority group and White students.

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**Special Education Access Matters**

Schools are the primary provider for diverse learners with autism.

40-80% of students with autism are first or only identified by schools.

**Why Equity in Access Matters for Students with Autism**

- Subjectivity of diagnoses/identification
- Differential access to health information and care
- Limited professional capacity to diagnose or identify in diverse populations
- Importance of early intervention and appropriate educational services for learning and wellbeing

Social justice is both a process and a goal that requires action. School psychologists work to ensure the protection of the educational rights, opportunities, and well-being of all children, especially those whose voices have been muted, identities obscured, or needs ignored. Social justice requires promoting non-discriminatory practices and the empowerment of families and communities. School psychologists enact social justice through culturally-responsive professional practice and advocacy to create schools, communities, and systems that ensure equity and fairness for all children and youth.

Adopted by the NASP Board of Directors, April 2017
The Goal
Fulfilling the spirit of special education: free appropriate public education following an individualized education plan in the least restrictive environment using research-based practices protecting parent rights allowing due process with zero rejects

Interrelated Dimensions of Autism Services

Policy
- Federal
- Case law

Preparation
- Pre-service
- In-service

Practice
- Assessment
- Intervention

University of Minnesota
Policy Shaping Autism Identification in Schools

Autism Classification Systems

• Health service providers:
  – Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)
  – International Classification of Diseases -10th Revision- Clinical Modification (ICD-1)

• In schools:
  – Federal and state special education law

Systems' criteria vary

Identification is required for many services

Identification in one system ≠ eligibility in another

Medical diagnosis not required for special education eligibility*
Autism under IDEA

- (i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child’s educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

- (iii) A child who manifests the characteristics of autism after age three could be identified as having autism if the criteria in paragraph (c)(1)(i) of this section are satisfied.
IDEA Disability Categories

- autism
- deaf-blindness
- deafness
- emotional disturbance
- hearing impairment
- intellectual disability
- multiple disabilities
- orthopedic impairment
- other health impairment
- specific learning disability
- speech or language impairment
- traumatic brain injury
- visual impairment

### Table 1: States ASD prevalence and ASD identification characteristics

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<th>Prevalence 3-5 (%)</th>
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</table>
Evaluators fail to recognize ASD or decide that difficulties are more appropriately associated with attributed to another category.

Implications

Special education categories drive services

Schools remain primary provider of Autism services for culturally and linguistically diverse students

Discrepancy between number of children medically diagnosed with ASD and the number of students receiving special education services

Possibility of under identification


Disproportionality and Autism

Over/Under identification

Inappropriate identification of eligibility categories

Fewer access to resources

Schools as first access point

Universities of Minnesota
Legal-Historical Context

Disproportionality in the Individuals with Disabilities Education Act (IDEA):

- **1997**
  - States required to define “significant disproportionality” (i.e., over-representation) and identify districts accordingly

- **2004**
  - Sig Dispro → 15% federal funds shifted to comprehensive early intervening
  - Review policies, procedures, practice

- **2016**
  - Equity in IDEA; Standard approach + state definition of thresholds
  - Identification of “root causes”

- **2018/19**
  - DeVos defers new rule
  - Judge stays deferral
  - DoJ appeals
  - To be continued...

Disproportionality in Identification

- Reduce identification
  - Child Find (under-representation, zero reject)

- Increase identification
  - Disproportionality (over-representation)
Why Does Disproportionality Policy Matter for ASD?

States and districts are expected to eliminate disparities.

When significant disproportionality is found, must reallocate federal funds to prevention.

May suppress identification of students from racially minoritized backgrounds.


Case Law Shaping Autism Identification in Schools (preliminary results)

Mollie Weeks, MA, University of Minnesota
Study Purpose

- Little attention is paid to issues of ASD identification within the legal system.
- Few studies using case law reviews to inform educational practices.
- Study Purpose:
  - Describe the status of ASD case outcomes and distill implications for families, educational policy, and educational practice.

Method

- Database: LRP Special Ed Connection
- Search Terms: ((autis%, eligib%), 5)
- Sequential Years: 1990-2016
- Exclusion Criteria:
  - Lower court decision or duplicate case;
  - Unrelated to IDEA;
  - Unrelated to eligibility or ASD; or,
  - Other reasons (e.g., OSEP policy memoranda)

Cases captured for initial screening
\((n = 1,397)\)

\[\rightarrow\]

Cases retained for review
\((n = 323)\)

\[\rightarrow\]

Cases meeting inclusion criteria
\((n = 191)\)

\[\rightarrow\]

Excluded during initial review
\((n = 1,074)\)

\[\rightarrow\]

Excluded upon further review
\((n = 132)\)

Administrative Court Cases
\((n = 163)\)

• ASD Eligible \((n = 31)\)
• Eligible Other \((n = 67)\)
• Ineligible \((n = 46)\)
• Not Decided \((n = 19)\)

Administrative Appeals Court Cases
\((n = 16)\)

• ASD Eligible \((n = 3)\)
• Eligible Other \((n = 8)\)
• Ineligible \((n = 4)\)
• Not Decided \((n = 1)\)

District Court Cases
\((n = 8)\)

• ASD Eligible \((n = 1)\)
• Eligible Other \((n = 5)\)
• Ineligible \((n = 2)\)

Appellate Court Cases
\((n = 4)\)

• ASD Eligible \((n = 1)\)
• Ineligible \((n = 3)\)
Demographics

Sex
- Male
- Female
- Both
- Not Reported

Age
- Ages 3-5
- Ages 6-9
- Ages 10-13
- Ages 14-18
- Not Reported

Plaintiffs and Decisions

Plaintiffs
- Single Family
- District
- Parents and District

Decision
- ASD Eligible
- Eligible: Other
- Ineligible
- Not Decided
Case Examples

**Needs not Labels**

- Banquette Independent School District (2011) - family brought a case in which they claimed ASD eligibility was improperly removed. Judge ruled, based on testimony, that the student’s ASD-like behaviors did not interfere with her ability to benefit from education; thus, qualifying her for SLD and SLI.
- Keller Independent School District (2012) - parents contended that removal of ASD label for ED was inappropriate. Judge ruled that, considering student’s mental health diagnoses and social skills services on the IEP, ED was an appropriate label.

**Considers labels to be a procedural issue which may not amount to a substantive violation of FAPE.**
Case Examples

Evaluation Deemed Appropriate

- Berkley County School District- issue stated that the Hearing Officer erred when ruling that the student qualified for ASD (outside expert testified otherwise). Judge ruled that the school psychologist and evaluation were credible in determining eligibility.

Evaluation Deemed Inappropriate

- Lancaster Elementary School District (2007)- ordered to develop and conduct an additional comprehensive evaluation for several disability categories (including ASD) as their previous evaluation did not assess the student in all areas of suspected disability.
Case Examples

Social Impairment

• District of Columbia Public Schools (2016)- issue was whether a boy was denied FAPE as he was not found eligible for services under DD or ASD. Court ruled that his social skills were sufficient and, thus, qualified for special education services under another category.

Communication Impairment

• Adelanto Elementary School District (2008)- issue was whether a boy was denied FAPE as he was not found eligible for services under ED, ASD, SLD, or SLI. Ruled that language deficits were due to SLD or SI.

**What Matters in Due Process Decisions?**

- Whether services deny FAPE beyond labels
- Persuasive experts
- Evaluation quality and appropriateness
- Demonstration of educational need
School Psychologists and Administrative Law Judges

Share similar duties:

Government actors who uphold civil rights

Determine or review issues of eligibility

Dual Problems: Ambiguity and Causation

<table>
<thead>
<tr>
<th>Ambiguity</th>
<th>Causation</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Laws can have multiple interpretations</td>
<td>• Determination of causation in eligibility and due process</td>
</tr>
<tr>
<td>• Challenges with determining educational performance and need</td>
<td>• Science avoids causal language</td>
</tr>
<tr>
<td>• High ambiguity in eligibility decisions and evaluations</td>
<td>• Cannot determine causation from tests, rating scales, etc.</td>
</tr>
<tr>
<td>• Ambiguity makes space for error in decision-making</td>
<td>• If we cannot infer causation, how can we practice ethically?</td>
</tr>
</tbody>
</table>

(Sadeh & Sullivan, 2017)
What to do?

- Place decisions within an ecological context
- Be vigilant for points vulnerable to bias in decision-making
- Problem-solving with low-inference decisions and malleable factors
- Consider disconfirmatory data
- Systematic decision-making rules and procedures

(Sadeh & Sullivan, 2017)
The “Triad” of ASD

- **What are we looking for?**
  a. **Lack of Communicative Competence**
     - Ability to communicate in a fluid and integrated manner
  b. **Impairments in Social Reciprocity**
     - Ability to have back-and-forth social interactions with a variety of people
  c. **Restricted, Repetitive Patterns of Behavior, Interests or Activities**
     - Insistence on routines
     - Repetitive motor behaviors (e.g., hand-flapping, vocalizations)

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Cultural and Language Considerations

> “While autism itself, the neuropathology of it, may not be culturally determined, our determination of those behaviours, and our interpretation of those behaviours is”

- Dr. Mandell (CHOP)
Research Pertaining to Cultural Influences of Behavior

- Zhang et al. (2006) noted that eye contact with adults and pointing with the index finger is considered inappropriate behaviors within the Chinese culture.
- Norbury and Sparks (2013) note potential cultural differences surrounding pretend play, public displays of emotion, and the extent to which children (especially boys) play with toy dolls.
- These culturally imbedded behaviors and experiences will significantly impact the results of ASD assessments.

How do we evaluate for ASD in the school setting using culturally and linguistically responsive methods?
IEP Teams

- IEP teams should include:
  - Parents/Caregivers
  - General education teacher
  - Special Education teacher
  - Speech Language Pathologist
  - Other school professionals as appropriate (e.g., occupational therapist, social worker, English language acquisition teacher)
  - Assessment interpreter (e.g., School Psychologist)
  - Student - when appropriate
  - Knowledge of Autism Spectrum Disorder!

Potential Components of Autism Assessment

- Record Review
- Interview with School Staff
- Interview with Child
- Parent interview
  - Medical history
  - Developmental/social history
  - Adaptive behavior
- Rating scales
  - Multiple informants/settings
  - Range of functioning
- Observations
  - Structured
  - Semi-structured/Unstructured
- Standardized testing
  - Cognitive/Developmental
  - Language/Communication
  - Academic
  - Executive function
  - ASD Specific Measures
  - Social Skills
Parent Interview

❖ Most critical component for CLD children!
❖ Child cannot have ASD symptoms only at school or in one language
❖ Learn about family expectations for communication
❖ Language history
❖ Cultural factors (immigrant, refugee, other family members living at home etc.)
❖ Considerations when working with an interpreter

Recommendations for Observations (Dennison et al., 2019)

• When conducting observations, consider:
  • The difference between the student’s skills communicating in the L1 and in English
  • Looking for symptoms of ASD that are not characteristic of a student acquiring a second language (e.g., lack of response to name, sensitivity to sensory stimuli, stereotypic behaviors)
  • The frequency and quality of attempts at social overtures, whether verbal or nonverbal
  • Observations in different settings (e.g. classroom, PE class, recess, lunch)
  • Conduct joint observations with another professional
Harris et al. (2014) ASD Assessment Study

- Authors conducted a comprehensive review of ASD assessments pertaining to culturally and linguistically responsive psychometrics and design
- Diagnostic tools assessed: ADOS, ADI-R, ASRS, CARS-2
- Screening tools assessed: ASQ:SE, ASSQ, GARS, M-CHAT, Q-CHAT, SCQ
- Findings: ASD screening tools had higher cultural and linguistic responsiveness than ASD diagnostic tools, practitioners need stronger tools for CLD populations

Reviewing the Psychometrics of an Assessment

- Theoretical basis and empirical information
- Standardization, reliability, and validity will be reported
- Standardization:
  - Norm sample (does it match or represent the intended population?)
- Reliability:
  - Evidence of score consistency
  - For example, test-retest reliability
  - Internal consistency reliability (high scores are generally above .80)
- Validity:
  - Adequacy of measuring the intended construct
  - Differential item functioning
  - Concurrent validity (such as giving scores on a similar ASD rating scale)
Psychometrics of ASD Assessments

- Mainly standardized with white, middle to upper class males
- Small samples of racially/culturally diverse children
- All Spanish language ASD diagnostic assessments are direct translations, not standardized
- What about other languages?
- Extremely limited research in this area

<table>
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<th>ASD Assessments Analyzed</th>
<th>Sample Size</th>
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<th>Latinx</th>
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<td>The Autism Diagnostic Observation Schedule ADOS-2 Module 1-4</td>
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**Selected ASD Specific Assessments - Most Commonly Used in Educational Evaluations**

- Childhood Autism Rating Scale, 2nd Edition (CARS-2)
- Gilliam Autism Rating Scale, Third Edition (GARS-3)
- Checklist for Autism Spectrum Disorder (CASD)
- Autism Diagnostic Interview-Revised (ADI-R)
- Autism Spectrum Rating Scales (ASRS)
- Social Responsiveness Scale (SRS-2)
- Autism Diagnostic Observation Schedule (ADOS -2)

  - Consider individual child, culture/language considerations, psychometrics, what assessments other team members are using, usefulness for intervention

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Limitations of the ADOS-2 in School Settings

- Training, expense, logistics with extensive testing materials, limitations of ASD teams that travel to do ASD assessment, limited research of ADOS with diverse cultural groups, not required for educational identification of ASD

Problematic Practices – ASD Assessment

- Not using the body of evidence
  - Weighting one tool/measure heavily
- Not adequately including families
- Not collaborating with multidisciplinary team members and integrating data
- Not involving ELA staff
- Using broad band screening measures solely (e.g. BASC)
- Building mental health staff not involved in assessment
- Not questioning the impact of culture and language throughout assessment
- Use of C-LIM (e.g., Styck & Watkins, 2013)
Problematic Practices – Assessment (cont.)

- Not considering other educational identification categories or health conditions (e.g. intellectual disability, SED, OHI, Anxiety)
- Limited or no consideration of trauma
- Retaining Developmental Disability eligibility until age 8
- Concerns of ASD in early childhood, although no ASD specific measures were administered
- No collaboration/communication with outside providers
- Requiring MTSS process prior to an ASD evaluation
- Not understanding the family and their expectations for their child as well as their knowledge of ASD

What can we do? Many things!

- Evaluate our own school and district data!
- Strong tier 1 and 2 practices
- Strong parent communication/home-school collaboration
- Good transition services between Part C and Part B (and preschool to kinder)
- MTSS Process (progress monitoring data points not required for an ASD eligibility)
  - What data should we be gathering?
  - Who should we involve?
- Special Education Evaluation/Services
  - Types of assessments selected
  - Interpretation of assessments
  - Culturally and linguistically responsive interventions
Practices to Promote – ASD Assessment

- Family interview! Developmental history is key!
  - This may occur with an interpreter

Practices to Promote (cont.)

- Obtain more qualitative information (more interviews, observations, comparisons to other like-bilingual peers, record reviews)
Practices to Promote (cont.)

- Consult with ELD teachers and SLP regarding the impact of language acquisition

Practices to Promote (cont.)

- If conducting standardized measures, take extensive notes about current areas of functioning and need. Paint a picture of that child’s current functioning in the report – much more useful than a number for intervention purposes
  - Standardized scores are not required for an educational identification of ASD, evidence of educational impact is

**Practices to Promote (cont.)**

- Rely on a body of evidence – one assessment should never "trump" other data

**Practices to Promote (cont.)**

- Do not wait to assess the child so they can obtain more English language proficiency

Practices to Promote (cont.)

- Utilize community resources (faith-based organizations, family services agencies, community partners with strong connections to the families to advocate for early identification)

Practices to Promote (cont.)

- Advocate for more assessments that have strong psychometrics with racially/ethnically and linguistically diverse children
Practices to Promote (cont.)

- All decisions about eligibility are made as a team. Arrange meetings with the team prior to the IEP to review data and consider if there are holes in the information gathered

Practices to Promote (cont.)

- As we currently don’t have optimal standardized ASD assessments for CLD populations, obtain more qualitative data and collaborate with the team in a more purposeful way
Thank you for joining us!

Questions?

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