Autism Diagnosis:
The Gateway to Intervention

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Introduction to the Problem

Autism Diagnostic Delays & Disparities

1. Phenotypic differences in those who receive later autism diagnosis emerge in the first year of life (see Zwaigenbaum & Penner, 2018 for review)

2. Behavioral phenotype becomes stable in second year with > 80% diagnostic stability by 14 months (Pierce et al., 2019)

3. Median age of autism diagnosis is after age 4 in US (Maenner et al; 2023)

4. Children from minoritized racial, ethnic, and socioeconomic backgrounds and rural regions diagnosed later or less frequently (Wiggins et al., 2020)

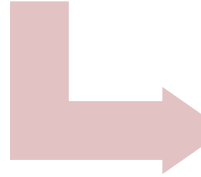# Delays in Diagnosis = Public Health & Military Problem

- Extended family separation
- Frequent moves
- Variable access to specialty care
- Family financial burdens
- Lack of social support

Cidav, et al., 2017; Kuhlthau et al., 2018; Lord et al, 2022; Zwaigenbaum & Warren, 2021

Shortage of expert clinicians
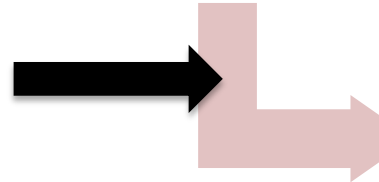
Time/cost intensive evaluation models

Long wait times

Travel burden

Delays in age of diagnosis

Medical diagnosis of autism is the GATEWAY to intervention

Delays in entry into intervention

Gateway Barriers

1. Specific diagnostic tests and assessments

2. Documentation of levels of support

3. Specialists as only valid diagnosticians

4. Modality of diagnostic evaluation

5. Regular diagnostic re-evaluation to continue intervention services

Barriers & Opportunities

Barrier # 1: Specific tests & assessments

Consensus suggests that, at minimum, evaluation of young children includes:

1. Developmental history & diagnostic interview

    –   Developmental history and current symptoms of autism, including how symptoms impact current functional status across settings

2. Behavioral observation

    –   Assess current social communication and interaction skills and behavior, which may include administration of a standardized tool

No one assessment tool is universally appropriate or sufficient for diagnosis

Barrier # 2: Levels of support

A diagnosis is not sufficient for intervention planning

Intervention planning must consider

1. The unique needs of the individual

2. Family priorities and cultural considerations

3. Community resources

DSM-5 Autism Severity Specifier/Level of Support is not an evidence-based method for determining support needs

Barrier # 3: Valid diagnosticians

Community-based diagnostic models reduce barriers to autism diagnosis

1. Improve equitable access

2. Reduce age of diagnosis

3. Result in accurate diagnosis

4. May improve access to specialists for children who require greater expertise

American Academy of Pediatrics now endorses primary care providers with training in application of DSM-5 autism criteria

Requiring diagnostic evaluation to be conducted by specialists is not aligned with current evidence

Barrier # 4: Modality of evaluation

Evidence-base for tele-assessment of autism is rapidly growing

1. Caregiver and clinic-based remote assessment tools available

2. Acceptable to families and clinicians

3. Used with high degree of clinician certainty

4. High rates of diagnostic agreement with in-person assessment

Requiring face-to-face diagnostic evaluation is not in line with current evidence

Barrier # 5: Diagnostic re-evaluation

Autism is lifelong developmental disability with high diagnostic stability

Repeated diagnostic evaluation for intervention authorization causes unnecessary burden on:

1. Families

2. Service systems

3. Payors

Authorization for intervention should consider changes in functional needs and goals of the individual and family

Opportunities to Open the Gateway

Consider the evolving evidence in updating requirements for diagnosis

- Flexible selection of diagnostic methods tailored to individual, setting, clinician expertise

- Expand definition of qualified diagnosticians

- De-couple diagnosis with intervention planning

Consider the impact of policies on equitable access to care

Thank You

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