# Findings on Children's Pathways To Diagnosis and Services

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#### **Disclosures**

- I have no personal financial relationships with commercial interests relevant to this presentation
- The views expressed are my own, and do not necessarily represent those of the NIH, NIMH, or the Federal Government





### Summary of topics to be covered

- Basic demographics of 4 (mutually exclusive) groups of children
- Preliminary data on:
  - Initial problems noted by parents
  - Age of child when first diagnosed
  - Types and number of services used by children
  - Types and number of medications used by children
  - Cohort differences in age when first diagnosed



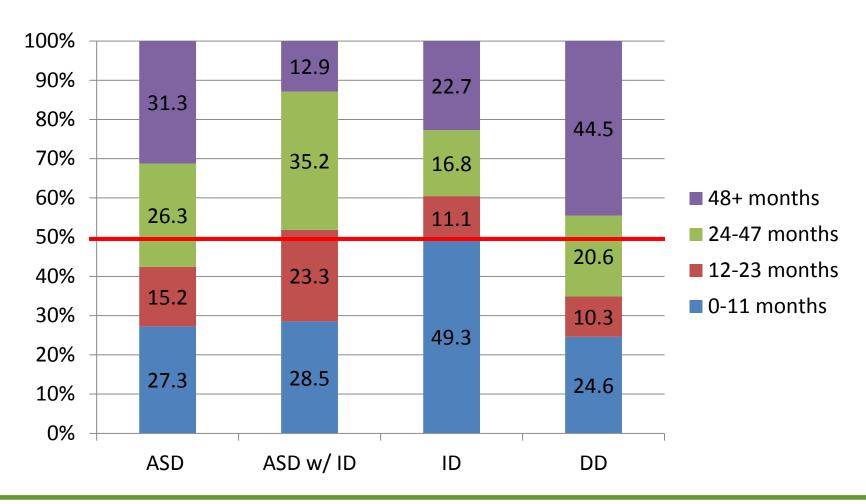
#### **Demographics**

|             | Autism Spectrum Disorder (N=1,117) | Autism Spectrum Disorder w/ Intellectual Disability (N=303) | Intellectual<br>Disability<br>(N=657) | Developmental<br>Delay<br>(N=1,441) |
|-------------|------------------------------------|---|---------------------------------------|-------------------------------------|
| Current Age |                                    |   |                                       |                                     |
| 6-11        | 56.4%                              | 48.7%   | 42%                                   | 50.3%                               |
| 12-17       | 43.6%                              | 51.3%   | 58%                                   | 49.7%                               |
| Gender      |                                    |   |                                       |                                     |
| Male        | 82.6%                              | 80.5%   | 51.4%                                 | 66.9%                               |
| Female      | 17.4%                              | 19.5%   | 48.6%                                 | 33.1%                               |





#### Child's age when parent was first concerned





#### Problems noted when parents were first concerned

- Categories assessed (20 items total):
  - Verbal Communication
  - Nonverbal Communication
  - Behavioral Difficulties
  - Learning and Understanding
  - Unusual Gestures or Movements
  - Motor Skills
  - Medical problems



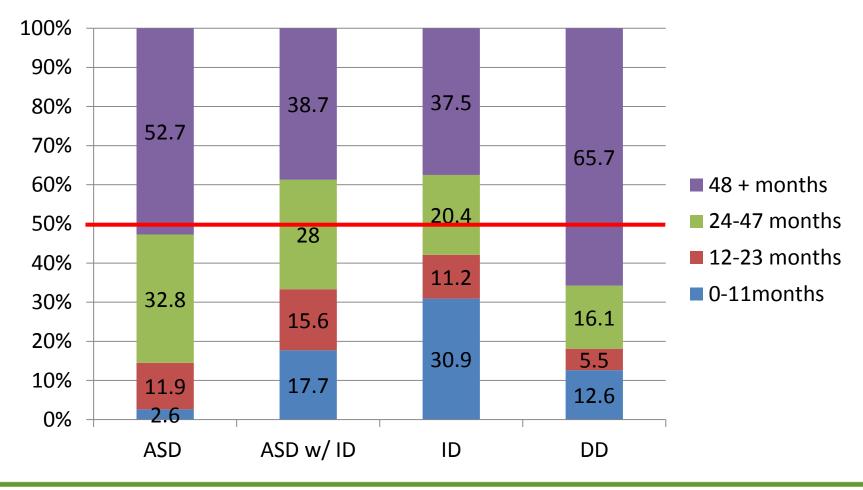


# Most commonly noted problems when parents were first concerned

| Autism Spectrum Disorder (ASD)   | ASD with ID                       | Intellectual<br>Disability (ID) | Developmental<br>Delay (DD)         |
|----------------------------------|-----------------------------------|---------------------------------|-------------------------------------|
| Behavioral                       | Verbal                            | Learning and                    | Behavior                            |
| Difficulties                     | Communication                     | Understanding                   | Difficulties                        |
| (90%)                            | (96%)                             | (87%)                           | (77%)                               |
| Nonverbal                        | Learning and                      | Verbal                          | Learning and                        |
| Communication                    | Understanding                     | Communication                   | Understanding                       |
| (87%)                            | (93%)                             | (85%)                           | (76%)                               |
| Learning and                     | Nonverbal                         | Behavior                        | Verbal                              |
| Understanding                    | Communication                     | Difficulties                    | Communication                       |
| (79%)                            | (90%)                             | (76%)                           | (61%)                               |
| Verbal<br>Communication<br>(74%) | Behavior<br>Difficulties<br>(86%) | Motor Skills<br>(78%)           | Nonverbal<br>Communication<br>(57%) |



#### Child's age when first diagnosed with ASD, ID or DD\*



<sup>\*</sup> Current diagnosis may be different from 1st diagnosis

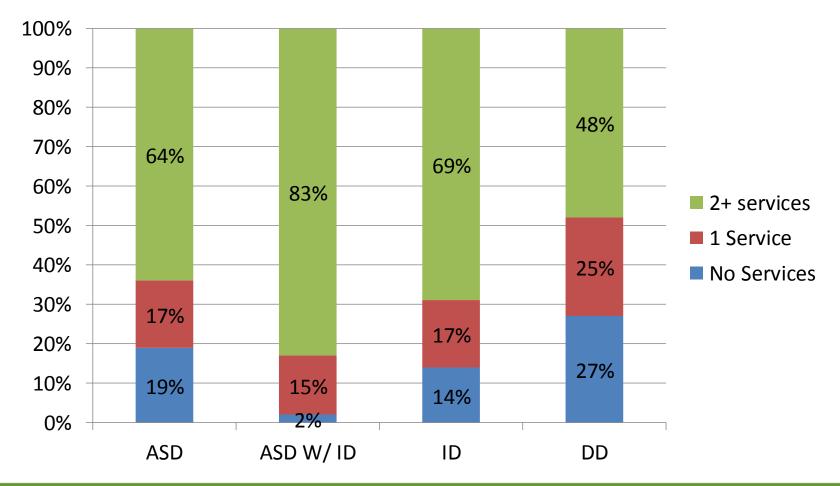


#### Types of therapy or training services used

- Services assessed:
  - Behavioral intervention or modification services
  - Sensory integration therapy
  - Cognitive based therapy
  - Occupational therapy
  - Physical therapy
  - Social Skills training
  - Speech or language therapy



#### Number of therapy or training services currently used





## Most commonly used types of therapy

| Autism Spectrum<br>Disorder (ASD) | ASD with ID                   | Intellectual<br>Disability (ID) | Developmental<br>Delay (DD)   |
|-----------------------------------|-------------------------------|---------------------------------|-------------------------------|
| Social Skills                     | Speech/Lang                   | Speech/Lang                     | Speech/Lang                   |
| (56%)                             | (81%)                         | (63%)                           | (40%)                         |
| Speech/Language                   | Social Skills                 | Occupational                    | Occupational                  |
| (51%)                             | (67%)                         | (54%)                           | (36%)                         |
| Occupational                      | Behavioral                    | Social Skills                   | Social Skills                 |
| (39%)                             | (44%)                         | (45%)                           | (31%)                         |
| Behavioral                        | Cognitive                     | Physical Therapy<br>(31%)       | Behavioral                    |
| (38%)                             | (43%)                         |                                 | (23%)                         |
| Using 1 or more services: 81%     | Using 1 or more services: 98% | Using 1 or more svcs: 86%       | Using 1 or more services: 73% |



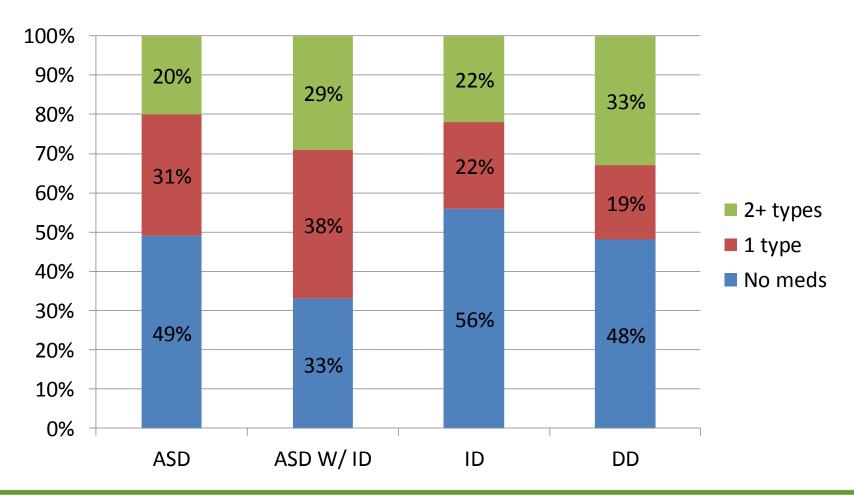
# Types of Medication Used

- Types of medication assessed:
  - Stimulant medications
  - Anti-depressant medications
  - Anti-anxiety or mood stabilizing medications
  - Anti-seizure medications
  - Anti-psychotic medications
  - Sleep medications





#### Number of types of medication currently used



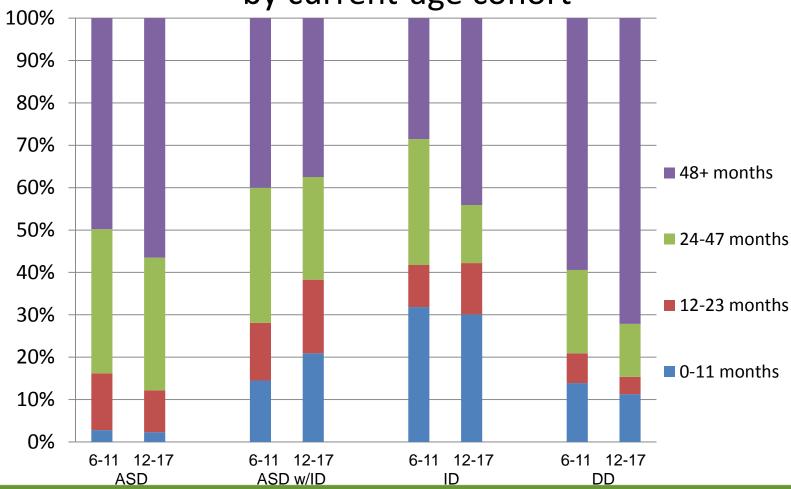


#### Most commonly used medication types by condition

| Autism Spectrum<br>Disorder (ASD)        | ASD with ID                               | Intellectual Disability<br>(ID)                | Developmental Delay<br>(DD)                   |
|--|---|--|---|
| Stimulant meds (30%)                     | Anti-anxiety/ mood stabilizing meds (34%) | Stimulant meds (17%)                           | Stimulant meds (35%)                          |
| Anti-anxiety/mood stabilizing meds (22%) | Stimulant meds (28%)                      | Anti Seizure Meds (16%)                        | Sleep meds (13%)                              |
| Antidepressant meds (17%)                | Antidepressant meds (27%)                 | Anti-anxiety/mood<br>stabilizing meds<br>(16%) | Anti-anxiety/mood<br>stabilizing meds<br>(9%) |
| Sleep Meds<br>(17%)                      | Sleep meds (23%)                          | Antidepressant meds (14%)                      | Antidepressant meds (9%)                      |
| On 1 or more meds:<br>51%                | On 1 or more meds:<br>66%                 | On 1 or more meds:<br>44%                      | On 1 or more meds:<br>51%                     |



Child's age when first diagnosed by current-age cohort





# Special Thanks!

- Stephen Blumberg
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