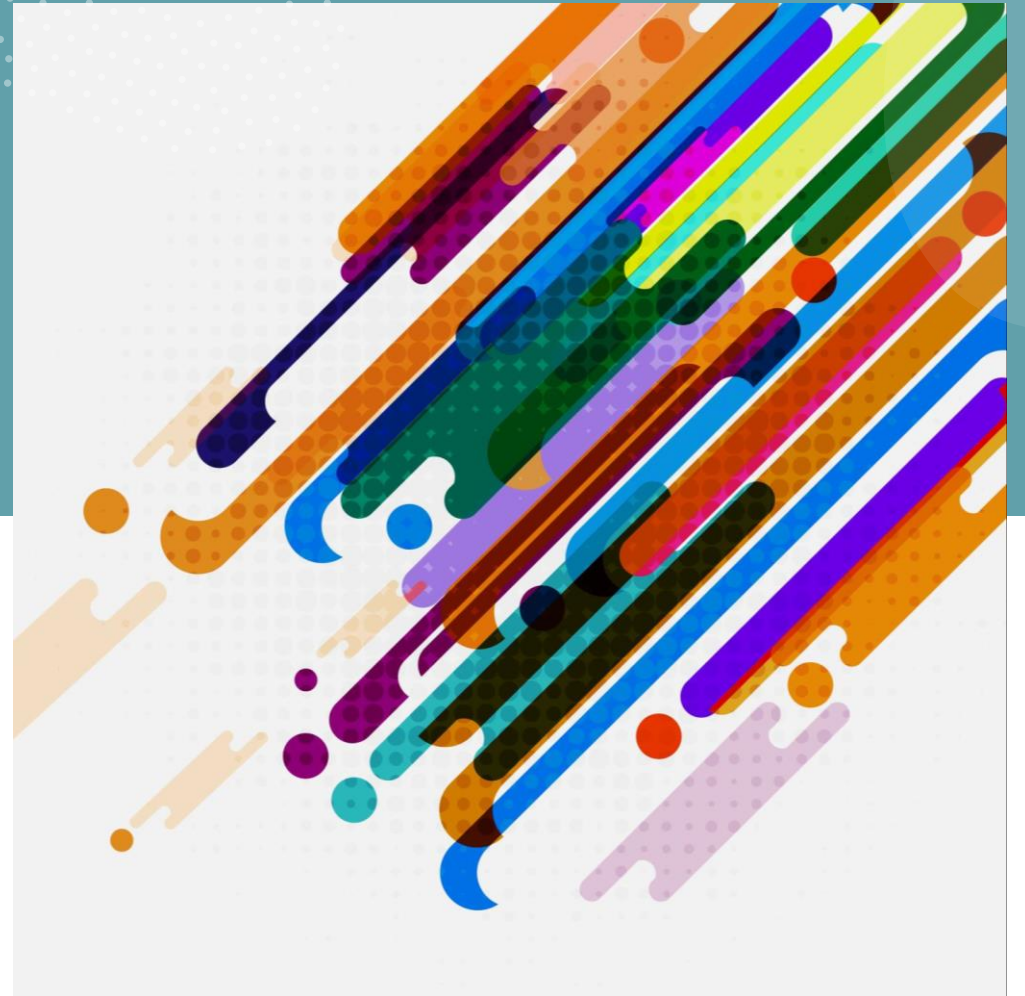


Co-Occurring Autism in Down syndrome: Considerations for Early Development

North Carolina Down Syndrome Conference

April 22nd, 2023

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UNIVERSITY OF
SOUTH CAROLINA



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**North Carolina
Down Syndrome Alliance**
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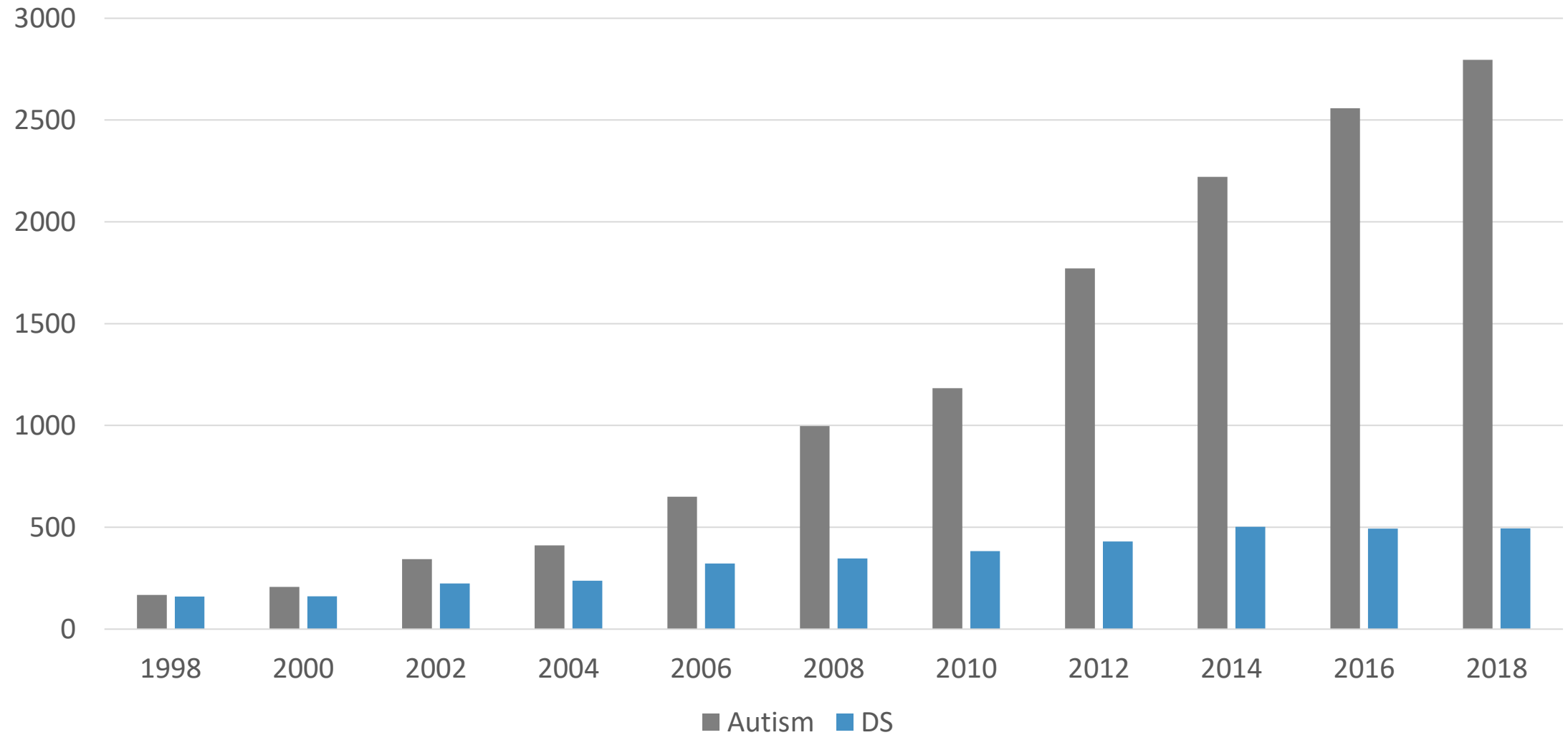


Down Syndrome Achievement Centers
educate. inspire. believe.

Charleston, SC

Research Patterns

Autism vs. Down Syndrome Publications in the Last 20 Years



What are the *Implications* of this trend?

Autism

- More Knowledge – risk factors, development, co-occurring diagnoses, phenotype
- Sources of variability
- Importance of early intervention
- Autism-specific interventions (Early Start Denver Model)

Down syndrome

- Minimal understanding of early development
- Risk factors
- Lack of Down syndrome-specific interventions
- Policy implications

Goals for Our Research

Refine

Identification and Behavioral Profile

Characterize

Factors of Risk and Resilience

Develop

Targeted Treatment Strategies



What is Autism??

Autism – Core Features

Social
Interaction

Social
Emotional
Reciprocity

Nonverbal
Communication

Relationships

Restricted & Repetitive
Behaviors

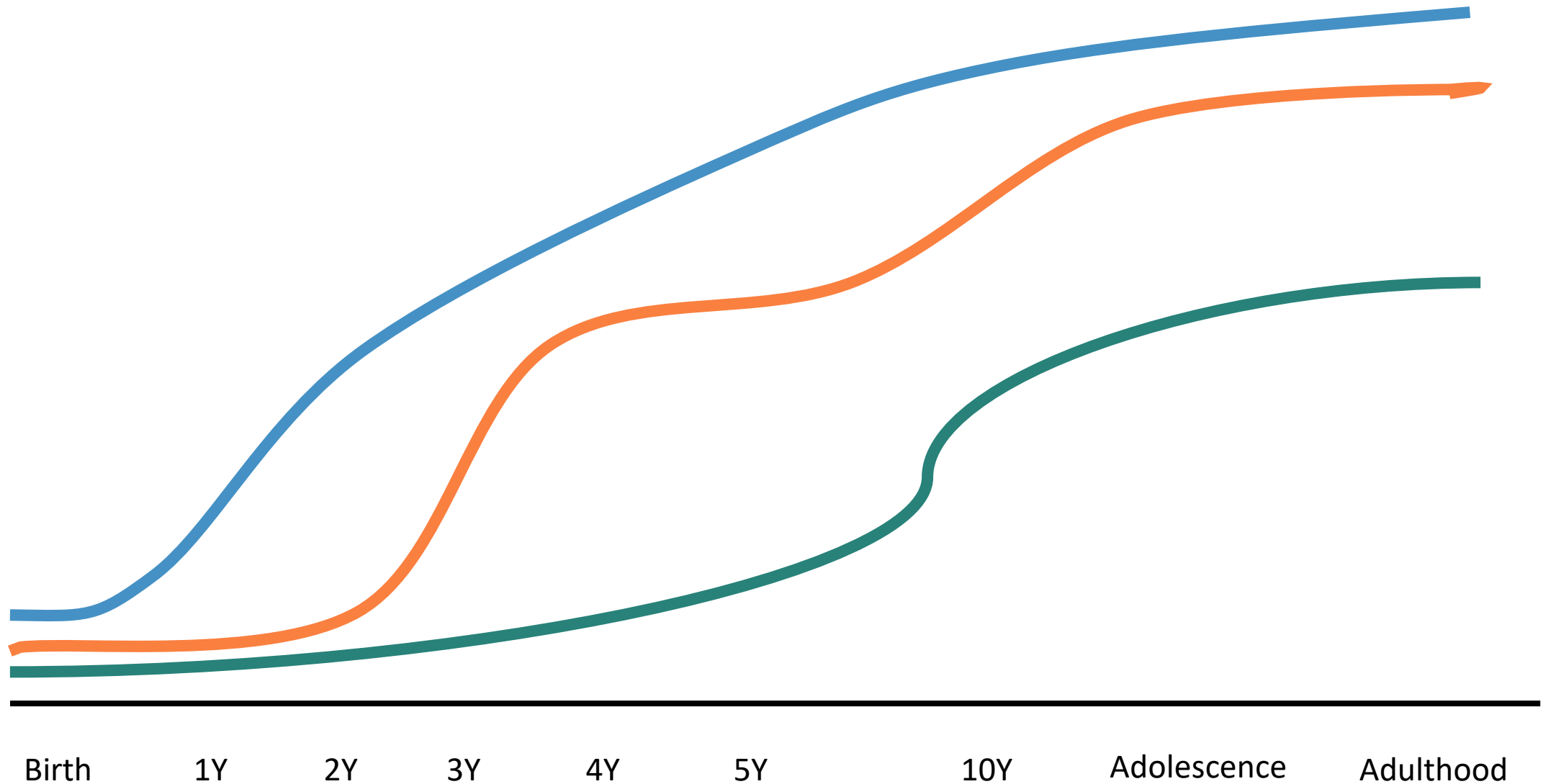
Stereotyped
Repetitive

Insistence on
Sameness

Restricted
Interests

Abnormal
Sensory

Importance of Early Detection



EARLY SIGNS OF ASD



First Year Signs

Signs

1

ATTENTION

Attention
Disengagement
Reduced
Attention to Faces
or Objects

2

SENSORY PROCESSING

Hypo or Hyper-
sensitivity to sound or
touch
Excessive Mouthing
Fine or Gross Motor
Delays or Atypical
Movements

3

SOCIAL FEATURES

Diminished
Response to
Name
Eye Contact
potentially
reduced

4

COMMUNICATION

Reduced
affection, less
interest in others
(reaching,
vocalizing,
imitating)



Second Year Signs

Signs

1

ATTENTION

Reduced attention
to whole object

Decreased
complexity of play

2

SENSORI-MOTOR

Repetitive motor
behaviors

Continued sensory
sensitivities

3

SOCIAL FEATURES

Reduced
interpersonal
synchrony

Decreased Social
Responsivity and
Initiation

4

COMMUNICATION

Reduced gesture
use



Third-Fifth Year Signs

Signs

1

ATTENTION

Over-focus on objects

Interest in unusual objects

Decreased complexity of play

2

SENSORI-MOTOR

Repetitive motor behaviors

Hand-flapping or Rocking

3

SOCIAL FEATURES

Peer interaction limited, restricted or unusual

Reduced interest in others

4

COMMUNICATION

Expressive

Language

Reduced or absent

How Signs May Differ in Down Syndrome

Timing

- May show similar features but take more time to emerge.
- Continued delay of expected milestones during 3 - 5th year rather than 18 - 24 months.
- Absence of functional play into 3 - 5th year.
- More prolonged lack of communication.

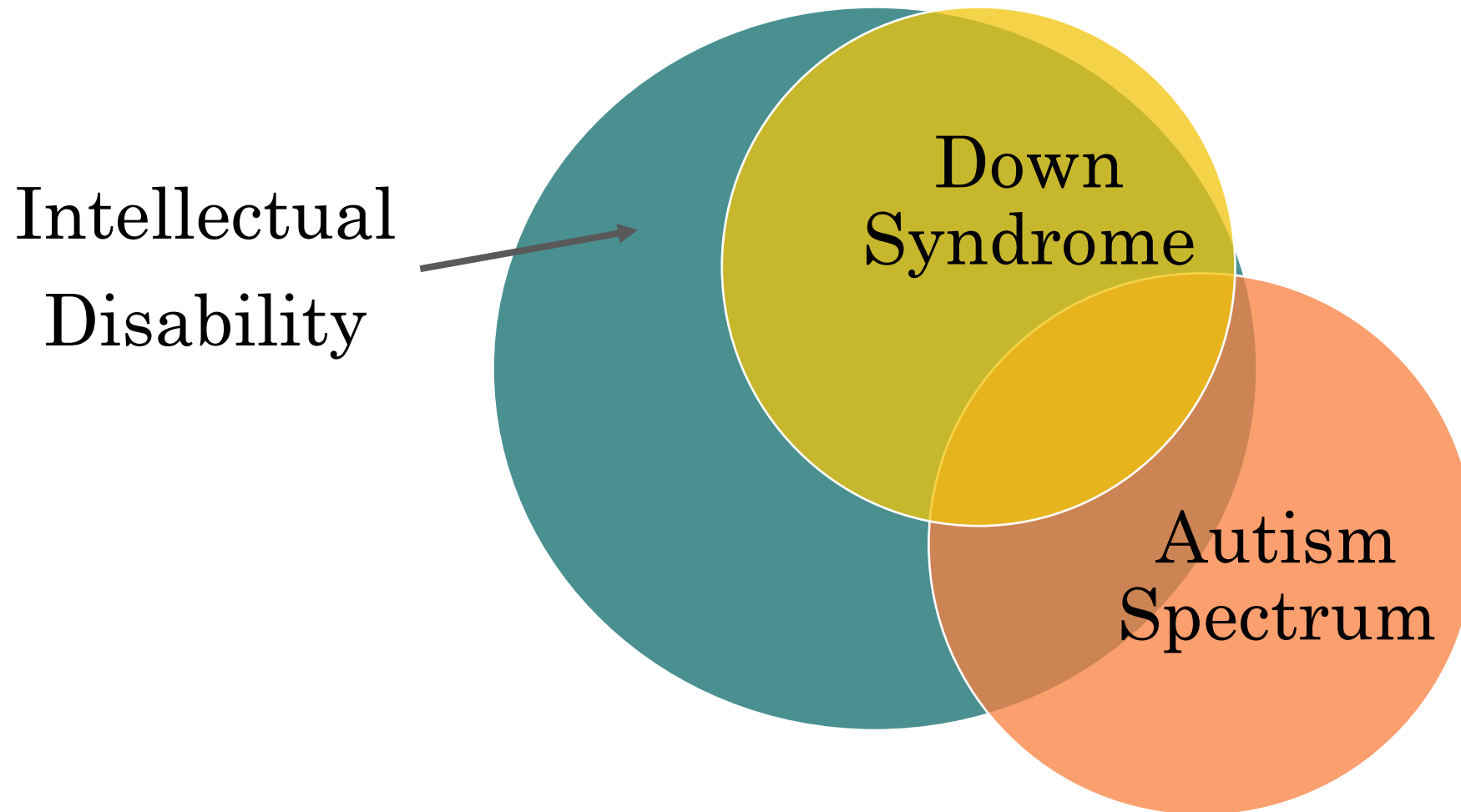
Quality

- Rather than absence of skill, is there an absence of skill foundation?
- For example, rather than lack of or minimal expressive communication, is there a lack of *intent to communicate*?

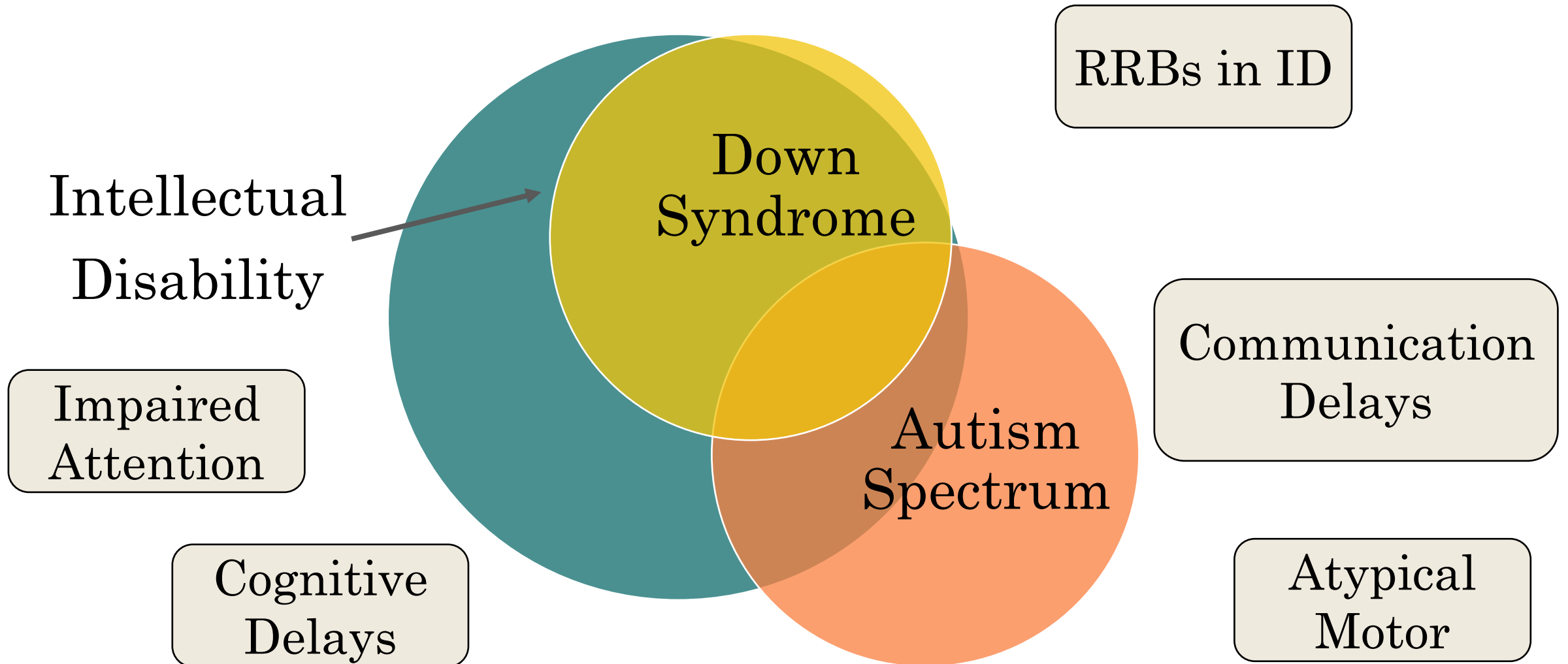
Coordination

- A child with DS may use eye contact and vocalization with a delay between these to communicate, rather than at the same time.
- A child with ASD may use only one mode to communicate, or no modes of communication.

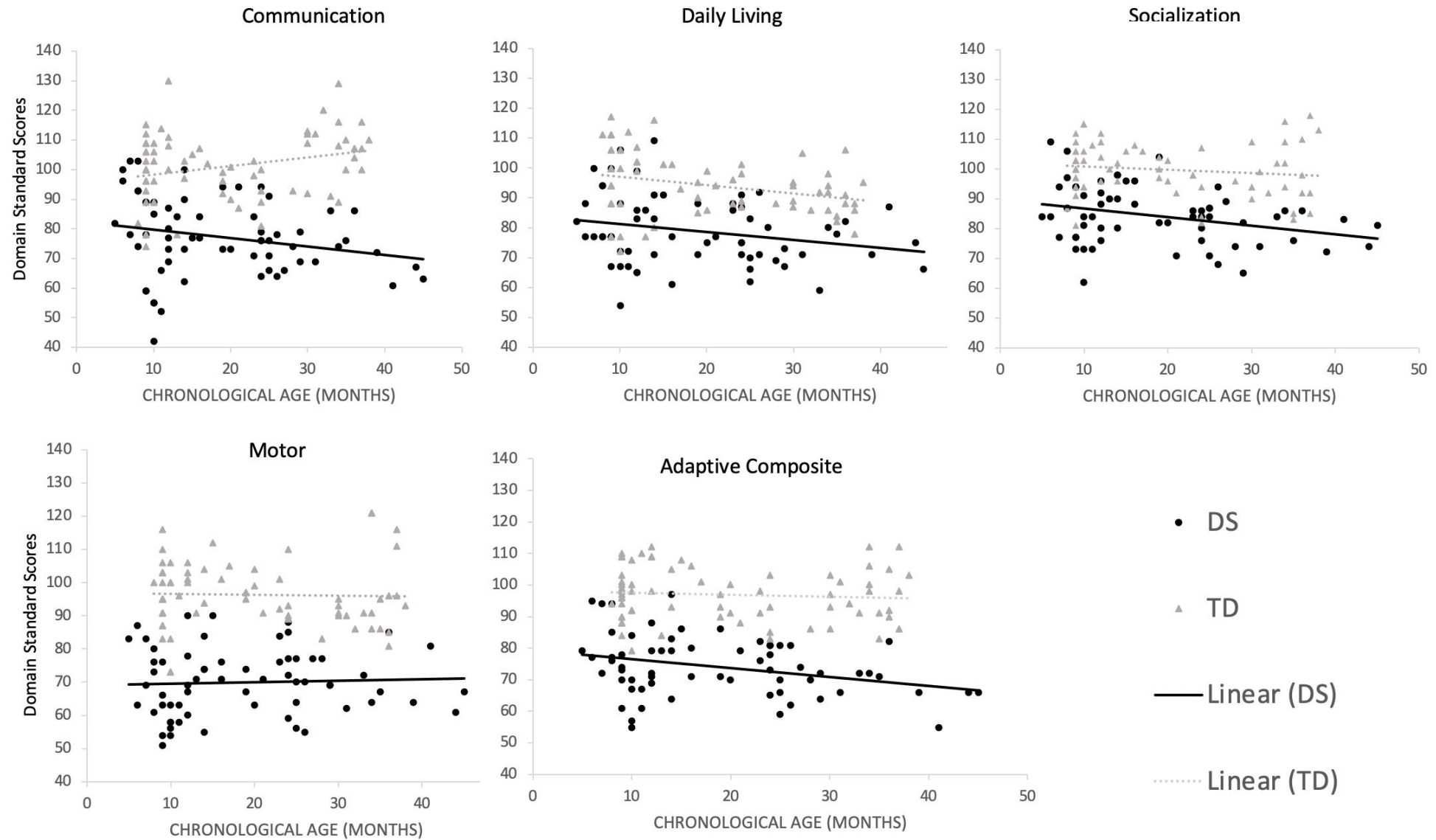
Phenotypic Overlap & Distinction



Phenotypic Overlap & Distinction



Parent Reported Developmental Trends



Diagnostic challenges in Down syndrome

Motor Delays

- Late Independent Walking
- Poor Motor Planning
- Gesture use, play

Medical Comorbidities

- Surgeries
- Effect of Physical symptoms on behavior
- Full Medical history
- Vision & Hearing

Info Processing & Attention Regulation

- Impaired engagement:
 - Showing
 - Giving
 - Joint Attention
 - Eye contact
 - coordination

Speech and Language

- Low Intelligibility
 - Difficult to catch words & phrases
- Use of ASL
 - Can resemble motor mannerisms

VIDEO EXAMPLES – Diagnostic Overlap

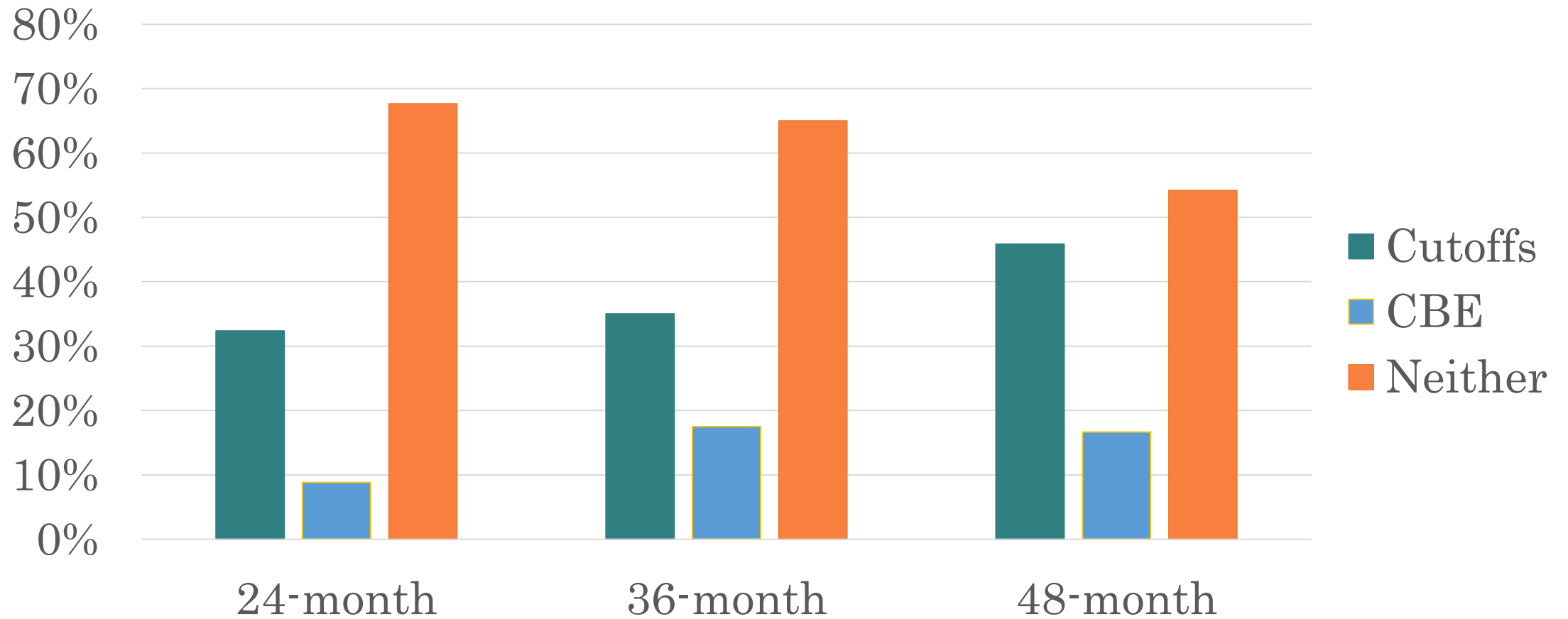
ASD in DS – what do we really know?

- Epidemiological study estimates a ~17% prevalence rate of co-occurring ASD in DS
- Knowledge is limited due to several factors
- Prior work suggests milder profile of symptoms
- Need to consider developmental and phenotypic variation
- Medical conditions



Proportions Across Diagnostic Method

Unpublished Longitudinal Pilot Data



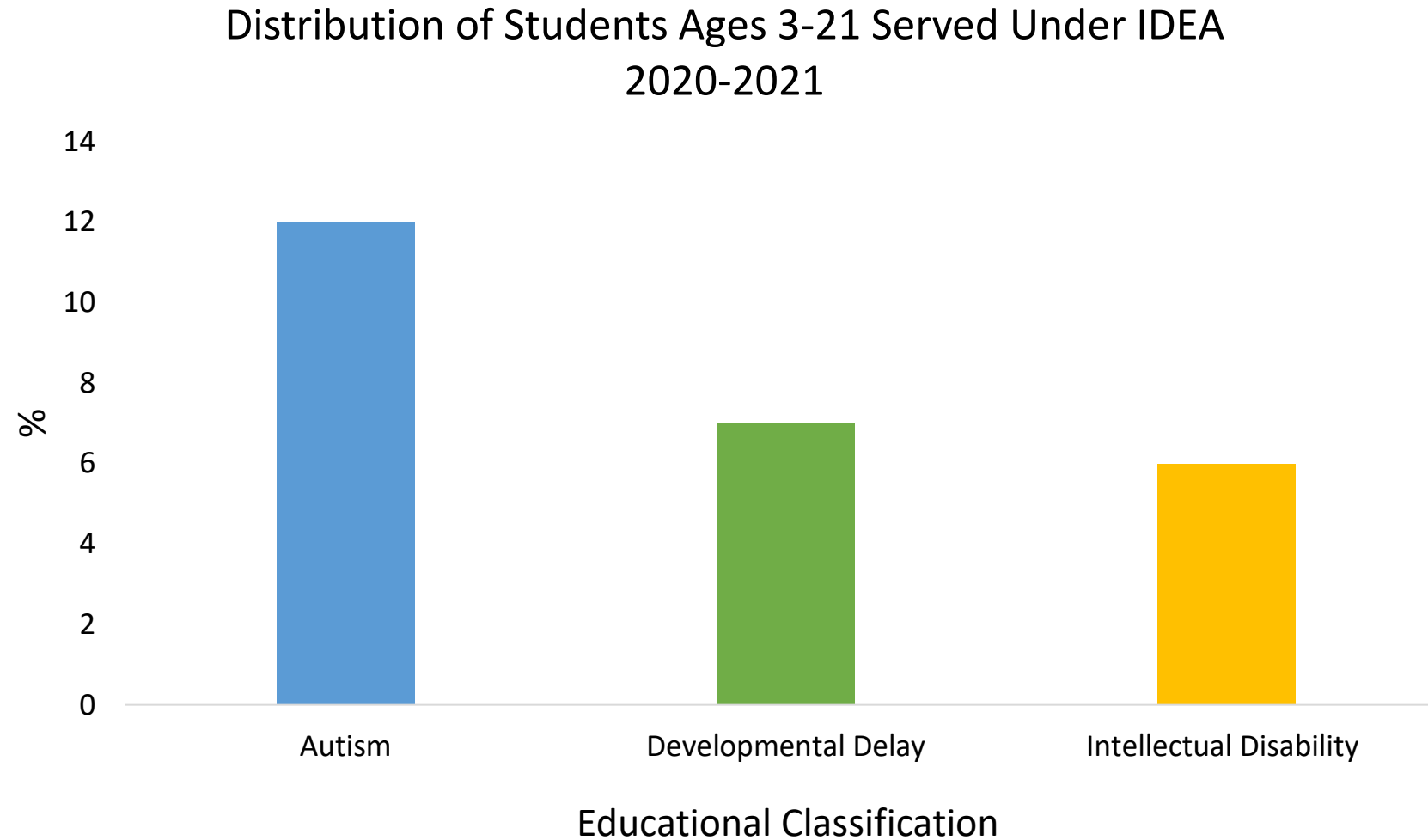


Implications for Families

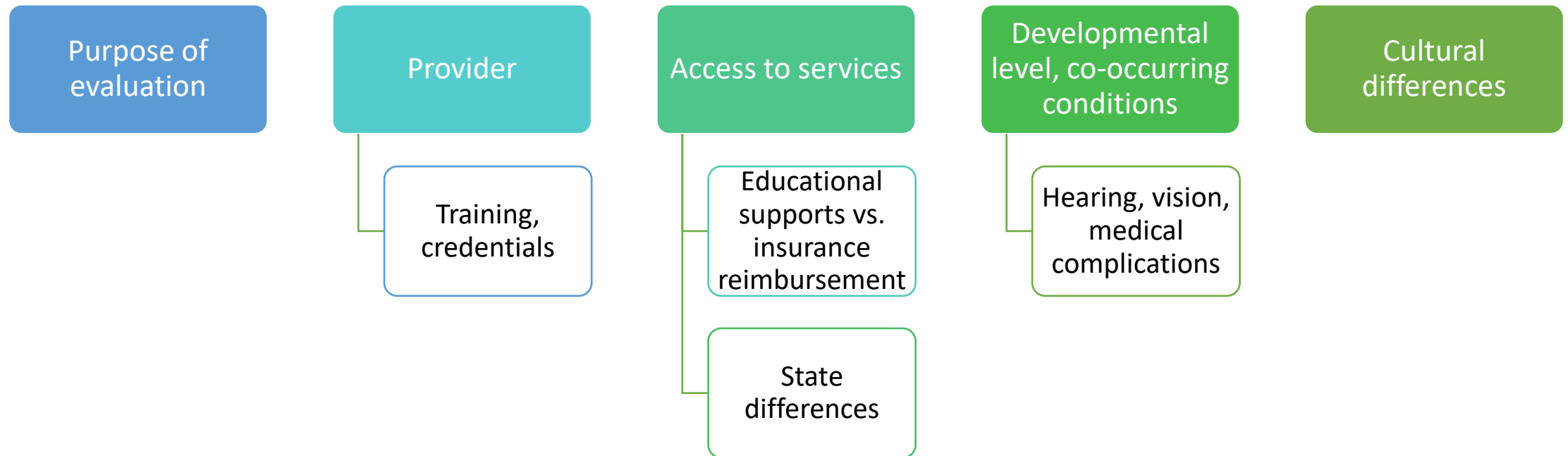
ASD in Medical vs. Educational Settings

	DSM-5/ICD-11	Special Education Eligibility
Diagnosis	Medical	Educational
Classification	Neurodevelopmental Disorder	Educational Classification/Disability
Purpose	Insurance reimbursement, provide information about strengths/challenges, determine severity and level of impairment, inform treatment	Give access to federally funded services within the public education system, determine educational needs, inform educational decisions (e.g., special education programming, classroom placement)
Criterion	Not better explained by another factor, interferes with and/or reduces the quality of social, academic, or occupational functioning	Not better explained by another factor, adverse effects of the disability on the child's educational performance that requires specialized instruction and/or related services

Educational Classification Patterns



Evaluation Considerations for Dual Diagnosis of Autism in Down syndrome



Supports & Services

School Based

- IFSP, IEP
- OT/PT/Speech
- Behavior management program
- Learning strategies/study skills support
- Social skills
- Adaptive equipment/special communication systems

Community Based

- Early intervention services (EI)
 - Family training
 - OT/PT/Speech
 - Service coordinator/case management services
 - Psychological services
- Applied Behavior Analysis (ABA)
 - Eligibility/requirements
 - Waitlists

EVIDENCE BASED SUPPORTS

General

North Carolina

Regional

SUPPORTING YOUR CHILD'S DEVELOPMENT VIDEO EXAMPLES

NATURALISTIC ENVIRONMENT AND EMBEDDING SKILLS INTO ROUTINE


ESDM

SYNCHRONY

VIDEO EXAMPLE OF RESPONSIVITY



What to do?

- 
- Monitor your child's development.
 - Watch her/his progress with early intervention services.
 - Watch for skills to emerge later than expected.
 - Keep routine medical check-ins for vision and hearing – difficulties in these areas can mimic features of ASD.
 - Don't put too much weight in unusual behaviors like flapping or looking closely at objects.
 - Children with DS may show a developmentally appropriate behavior like flapping longer than neurotypical children.
 - Encourage your child to give equal amounts of attention to people and toys – especially if you notice extra attention to one over the other.

Questions?

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