Part II. Down Syndrome and CVI: Two Diagnostic Journeys

Friday, June 5, 2026 I 10:15-11:30 am

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Important Take Away Points:

1) CVI in DS generally **occurs from birth**,
   a) the child does not know they see any differently than those around them, they just manage life with **unpredictable visual function**.
   b) The family also doesn't know about their child's vision issues and therefore must figure it out by **watching and interpreting behavior**.

2) CVI has only recently been recognized in DS,
   a) many older children, teens, and adults with DS likely have undiagnosed CVI.
   b) Their behaviors have likely been **misunderstood and misdiagnosed**.

3) **Diagnostic overshadowing** happens when we look for one overarching diagnosis to explain symptoms and behaviors.
   a) It makes it easy to attribute visual behaviors related to CVI to Down syndrome alone.

4) **Stereotypes of people with DS** are built on public exposure to individuals who are cute, sweet, higher functioning, so when challenges arise the families of those children may feel like they have failed and that they don't belong, and they may retreat to the shadows and not participate in the DS community.
   a) This is how we miss important diagnoses that affect more people than we know, like CVI!

Next Steps:

1) Observe and consider your student with Down syndrome

   a) Goals from IEP

   b) Challenging behaviors that may be preventing independence, productivity, and happiness

   c) Activities of daily living that they are currently working on.

2) Consider that lack of **visual and/or hearing access** may be impeding progress in these areas.

3) Implement Visual Support Strategies:
   a) Make it Easier Strategies
   b) CVI Now
   c) TSBVI

4) Monitor whether progress becomes easier.
   a) If so: This indicates that challenges and behaviors are at least partly **rooted in vision**

5) Continue to implement visual supports as part of program