Intellectual Developmental Disorder (IDD)

Presenting Problem:

A participating primary care provider (PCP) reached out to the Wisconsin CPCP regarding a 13-year-old male patient diagnosed with ADHD and disruptive behaviors, including aggression towards peers at school. While stimulant medications have provided some modest benefits, the patient has struggled with side effects, such as agitation, on Adderall XR 10mg and Concerta 18mg. Neuropsychological testing revealed a Full-Scale IQ of 52, consistent with a diagnosis of moderate intellectual developmental disorder (IDD). The child's caregiver expressed concern: "Even when he's less hyper, he still doesn't act his age, and he still hits kids!" The PCP seeks advice on how to proceed.

Consultant's Response:

There are likely multiple factors contributing to this patient's symptoms, particularly related to his IDD. Below are some considerations:

1. **Medication Sensitivity in Patients with IDD:**

   Children with IDD may have heightened sensitivity to medication side effects, such as irritability, cognitive impairment, or sedation. In those with cognitive limitations, sedative side effects may impair learning and memory. Additionally, medications intended to control behavior (like stimulants) can sometimes worsen agitation or disinhibition, especially in children with cognitive challenges.

   Lower Doses May Be Required: Children with IDD often need lower doses of medication to achieve the desired clinical effect while minimizing side effects.

   Medication Options for ADHD:
   For this patient, consider the following options:

   Discontinue any long-acting stimulants and initiate a trial of methylphenidate IR, dosed twice daily (q AM and q noon). Start with a low dose, such as 2.5 mg per dose, and increase as needed and tolerated approximately every 7 days. The patient may also require a small dose on an as-needed (PRN) basis after school.
   If stimulants are not effective or tolerated, consider a non-stimulant option such as guanfacine ER or atomoxetine, which are often better tolerated in non-neurotypical patients.

1. **Behavioral Expectations and Developmental Context:**

   It is essential to compare the child's behavior and functioning to others at his cognitive level, rather than his chronological age. This approach helps avoid pathologizing behaviors that are developmentally appropriate for a child with developmental delays. Psychiatric diagnoses should be made based on behaviors that are beyond the child's developmental level and cause significant impairment.

   Children with IDD may exhibit social behaviors (e.g., bullying, aggression) that are interpreted as socially inappropriate but may be developmentally typical for their cognitive level.

   Before prescribing medication for behavioral problems (such as aggression), non-medication interventions—such as **social skills training, behavioral interventions, or psychotherapy**—should be explored and deemed insufficient.

   Further assessment of the patient's aggressive behavior at school is warranted.

Caregiver Education: Caregivers may benefit from additional education about IDD to better understand their child's behaviors and functional abilities across various settings.

Knowledgeable caregivers are essential for identifying symptoms and functioning across settings, as well as constructing a picture of the child's baseline strengths and challenges. Caregivers can qualify and quantify the symptoms in terms of change from baseline (e.g., new behavior, increased intensity or frequency of old behavior, new contexts in which behaviors occur) and note whether there is any discrepancy across settings or with different caregivers.

Teaching Points:

1. **Prevalence of Psychiatric Disorders in Children with IDD:**

   Psychiatric disorders are three times more common in children with IDD compared to those with typical development. High rates of oppositional defiant disorder (ODD), ADHD, and anxiety disorders have been reported. Misdiagnosis can occur when behaviors are compared to chronological age instead of developmental level.

2. **Limited Evidence for ADHD Treatment in IDD:**

   Research on ADHD treatment in children with IDD is limited. Most medication trials exclude children with IDD, making it difficult to determine the most effective approaches for this group.

   Two large randomized controlled trials (RCTs) have evaluated the efficacy of methylphenidate IR in children with intellectual and developmental disabilities (IDD). The results indicated that approximately 40% of children with ID/IDD and an ICD-10 diagnosis of hyperkinetic disorder experienced benefits, with effect sizes ranging from 0.39 to 0.52. These effect sizes are notably lower than the 0.8 to 0.9 effect sizes observed in typically developing children.
   Common side effects in these trials were similar to those seen in children without IDD, primarily appetite suppression and sleep disturbances.