



Understanding WAGR Syndrome: A Neurodevelopmental Perspective

Key points for families with children who have WAGR syndrome

Based on Dr. Ngozi Oluonye's presentation at WAGR Weekend UK 2025

1. What is WAGR syndrome and how does it affect development?

- **WAGR syndrome** is a rare condition that can affect vision, learning, and behavior
 - **Vision problems** are common and can impact how children move, learn, play, and communicate
 - Developmental delays or challenges with learning, speech, or behavior are also common
 - No two children are exactly alike—strengths and challenges can vary widely
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2. Why vision matters for development

- Good vision helps children explore the world, learn language, and build relationships
 - When vision is limited
 - **Motor skills** (crawling, walking) may develop more slowly
 - **Language and communication** may take extra support
 - **Social skills** may not develop in the same way as children with typical vision
 - Children with WAGR have a higher risk of **autism-like traits** and **ADHD** (trouble with attention, sitting still, or waiting)
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3. Common developmental and behavioral challenges

- Some children may
 - Avoid touching new things
 - Have trouble sleeping or eating certain textures
 - Use repetitive movements or play rigidly
 - Speak in sentences that don't always fit the situation
 - Teens may experience **anxiety, depression, or meltdowns**, especially at puberty. Warning signs include irritability, school refusal, withdrawal, or self-harm behaviors
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4. How doctors assess children with WAGR

- **Special vision tests** to measure even very low levels of sight
- **Developmental assessments** to check language, thinking skills, social skills, and learning
- **Behavioral assessments** to look for autism, ADHD, or anxiety
- **Multidisciplinary teams** (eye doctors, pediatricians, therapists, teachers) work together to understand each child's needs

5. What parents can do to help

- **Start early** If you notice delays in vision, speech, or movement, don't "wait and see." Early therapy makes a big difference.
- **Keep records** Write down when behaviors happen, what triggered them, and how your child responded. Short videos can help doctors and teachers understand what you see at home.
- **Use structured tools** The *Developmental Journal for Babies and Young Children with Visual Impairment (DJVI)* gives step-by-step guidance for encouraging skills and tracking progress.
- **Encourage exploration**
 - Let your child use their hands to learn about objects and textures
 - Play sound-based games to help them locate things by hearing
 - Offer toys or items with different shapes, temperatures, and sounds
- **Support communication**
 - Talk out loud about what's happening around your child ("We're pouring juice now—it sounds fizzy!")
 - Encourage back-and-forth play, even if it's just making noises together.
 - Praise attempts to interact—even small ones like turning toward a sound.
- **Plan for school success**
 - Ask for an education plan with specific accommodations
 - Work with teachers to ensure seating, lighting, and materials fit your child's vision needs
 - Involve a Qualified Teacher of the Visually Impaired (QTVI) if available
 - **Look after yourself** Parenting is demanding. Support groups, respite care, and talking with other parents can make a huge difference.

6. Understanding behavior

- **Use the ABC approach** to decode behavior
 - **A (Antecedent):** What was happening before the behavior? Were they tired, hungry, overwhelmed?
 - **B (Behavior):** What exactly did they do? (Example: threw a toy, screamed, hid under the table.)
 - **C (Consequence):** What happened afterward? Did the reaction calm things down or make it worse?
- **Behaviors are often communication.** Children may act out because they're anxious, overstimulated, or can't express what they need
- **Behavior challenges are not “bad behavior.”** They are signals that something is too hard, confusing, or uncomfortable
- **Early professional help matters**
 - Share concerns with your GP or pediatrician so local services (community pediatrics, therapists, CAMHS) can get involved
 - If needed, ask for behavior assessments adapted for vision impairment.
- **Work as a team** Consistent strategies between parents, teachers, and therapists prevent confusion and help children feel secure

7. Supporting the whole family

- **Parents need support too** Caring for a child with complex needs is exhausting. You deserve help, not just your child.
- **Siblings matter** Brothers and sisters may feel left out or frustrated
 - Spend individual time with them
 - Let teachers know they might need extra emotional support
 - Consider sibling support groups or young carer programs
- **Use respite care and networks**
 - Short breaks help you recharge
 - Other parents of children with WAGR or vision impairment can share practical tips
- **Celebrate strengths** Focus on what your child *can* do, not only the challenges. Encourage hobbies, talents, or interests they enjoy.
- **Help your child “own” their differences** Children feel better knowing they're not the only one with unique needs. This builds confidence and resilience.

8. Looking ahead

- **Steady progress is possible** With the right therapies and support, children with WAGR can keep learning new skills.
- **Transition planning is important** As your child grows, prepare for changes in school, medical care, and independence.
- **Key focus areas**
 - **Education** Keep updating learning plans as your child's needs change
 - **Mental health** Watch for anxiety, sadness, or withdrawal—teens especially need emotional support
 - **Social inclusion** Encourage friendships, community activities, and hobbies
 - **Advocacy** Help your child learn to speak up for what they need (or speak up for them until they can)
- **Adulthood is the next chapter**
 - Look at vocational programs, further education, or supported living options
 - Keep coordinating health care as they move from pediatric to adult services

Bottom line *Children with WAGR syndrome thrive when families, doctors, schools, and communities work together to understand their needs, celebrate their strengths, and plan for the future.*

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