OPAL Pearls

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Welcome to the first installment of OPAL Pearls - a new quarterly publication by the consultants of the Oregon Psychiatric Access Line.

Our purpose is twofold:

1. To share insights or summary information on topics frequently raised by our callers.
2. To remind you of our availability and make it easy for you to share our contact information with colleagues.

This first edition is longer than future ones since we want to introduce you to our Developmental Behavioral Pediatrics wing of OPAL and because autism is currently much in the public eye.

We welcome any feedback and suggestions for future topics.

Is this youth on the autism spectrum?	1. Parents, extended family members, and service providers often question whether a child might be on the autism spectrum. 2. If the diagnosis is uncertain to you, a referral to a Developmental Behavioral Pediatrician may be warranted. Currently, the wait times to see such specialists in Oregon are approximately 12-18 months. 3. If a referral is made, please consider also calling OPAL-K-DBP, which offers **scheduled phone consultations** lasting 30 minutes, facilitating discussions between providers and OPAL DBPs. We are particularly eager to assist primary care providers in initiating beneficial services and/or medications promptly, rather than waiting a year or more for an official diagnosis. This service is not intended to replace the official in-person consultation but serves as an additional resource while awaiting that referral. 4. Currently, OPAL DBP consultations are underutilized; we strongly encourage you to take advantage of this service and disseminate this information among your colleagues throughout Oregon. **OPAL-K-DBP can be reached at 503-346-1000.**

How to approach diagnosing youth who struggle with social interactions

By Dr. Randy Phelps, Developmental Behavioral Pediatrician and OPAL-K DBP consultant

Currently, there is a high emphasis on screening for and diagnosing autism, or ASD, at the earliest possible age. The implication suggests that early diagnosis of autism is particularly crucial for enhancing functioning. Though all neurodevelopmental disabilities deserve to be properly diagnosed and treated, all of these conditions, including autism, are facets of neurodiversity, not illnesses. Our objective in this field is not to cure autism, but to enhance the functioning of individuals with autism and to advocate for necessary accommodations and services.

Screen

1. The most frequently recommended screens are the: M-CHAT and ASQ/ASQ-SE
2. Remember that the purpose of screening is to cast a wide net, to make sure that people who might have a given condition undergo diagnostic testing, and, if indicated, treatment. Screening tests, by definition, have high sensitivity and low specificity; in other words, a good screen should pick up the vast majority of people with the condition of concern, but should also pick up a large number of people who do not have the condition.

Consider other diagnoses. Accurate identification of these diagnoses can be very helpful, even essential, in identification of appropriate and effective interventions. Sometimes parents or the patient can have preferences for one diagnosis over another possibly due to stigma or to which diagnoses carry access to which kinds of support. This can be challenging to navigate. Here are common diagnoses that we, as DBPs, consider when we evaluate children for possible autism.

1. **Intellectual disability**: This diagnosis is now more stigmatized than autism; the drop in ID prevalence in recent years mirrors autism's rise.
2. **Global developmental delay**: This is a diagnosis of the preschool age range, this can feel too vague for a lot of parents, almost like no diagnosis at all.
3. **ADHD**: This diagnosis carries a stigma. Parents may assume that medication automatically follows and may oppose this diagnosis for this reason.
4. **FASD** (fetal alcohol spectrum disorder): This condition remains under-diagnosed and under-recognized. Due to stigma, parents may look for an ASD diagnosis as an absolution/exclusion from an FASD diagnosis. Yet there

is evidence that choline might promote some brain healing, so avoidance of this topic is tragic. Additionally, many kids with FASD don't access DDS and other services for which they would qualify.

5. **Tourette syndrome**: This is also a developmental disability that impacts a wide range of functioning. Though defined by tics, it is highly associated with various characteristic symptoms that have significant impact, including ADHD symptoms, OCD symptoms, emotional lability, sleep disorder, etc.
6. **Other mental health conditions**, including depression, anxiety, adjustment disorder, PTSD, reactive attachment disorder, and other trauma and stress related disorders may have enough symptom overlap to cause a child to have a positive screen for autism.
7. Autism experts highlight the importance of maintaining a broad differential diagnosis when children screen positive and are referred for autism diagnostic assessment. Bishop and Lord (1) have recently commented that, although identifying autism is important, there is no one treatment or service that is always needed or always effective in supporting people with autism. Given the extreme heterogeneity that characterizes the autism population, the diagnosis itself is less likely to guide treatment planning or provide meaningful information about prognosis than a comprehensive profile of a child's cognitive, language and adaptive behavior skills, as well as medical and psychiatric problems, They point out that families have the right to expect that recommendations for services reflect individual difference in strengths and difficulties, and also that these challenges may be related to conditions other than or comorbid with autism, such as intellectual disability, ADHD, or depression.
8. Finally, there are, even in 2025, normal but quirky kids, or temperamental little kids, but it can be very challenging to communicate such impressions to parents these days; parents may feel that you don't believe them or are being dismissive of their concerns.

Could someone have misdiagnosed autism in my patient?

1. An important paper out of OHSU last year (Duvall et al) found that almost half of children with reported community-based autism diagnoses were found to not qualify for research-standard autism diagnosis (2). Fully 47% of children with community-based ASD diagnoses did not meet ASD criteria by expert consensus. ASD+ and ASD- groups did not differ in age, gender, ethnicity/ race. Increased reported psychiatric disorders in the ASD- group suggests psychiatric complexity may contribute to community misdiagnosis and possible overdiagnosis of ASD.
2. Eric Fombonne (3) points out that there may be broad societal forces contributing to the phenomenon of overdiagnosis. Although many would argue that the priority is to provide access to services for children presenting

with neurodevelopmental disorders and that the consequences of underdiagnosis are far more deleterious than those due to overdiagnosis, this does not mean that erroneously diagnosing a child with ASD is harmless. At the individual level, carrying an ASD diagnosis may unduly constrain one individual's range of social and educational experiences and have long-lasting effects on his/her/their identity formation. At a population level, the unjustified use of intensive services raises concerns about equity and fairness in services access for children who have neurodevelopmental disorders other than autism and struggle to access support services that they need as much as their peers with ASD.

Does the diagnosis of autism give a child special access to support services?

1. Many parents assume that an autism diagnosis is needed to access services and supports. This is, in part, true but the whole story is more complex. From an educational standpoint, yes, an autism label may help a child to access more services, but the label incorrectly applied may route a child to a more restrictive environment than necessary or appropriate.
2. Since passage of the ABA (Applied behavioral analysis) law in Oregon (in 2014), a medical diagnosis of autism is helpful in accessing that one particular modality of therapy, but there is a bottleneck for ABA services and ABA is not always appropriate for every child with ASD.
3. Sometimes an autism diagnosis is sought to help a child access Developmental Disabilities Services; ASD is a qualifying label for such services, but it is not the only one—so ruling out autism is not tantamount to denial of such services (though many families, and even professionals, seem to think this).
4. Unfortunately, referrals for behavioral and mental health services may be jeopardized by an autism label. Technically, it is illegal discrimination to deny MH referrals on the basis of ASD diagnosis, but it happens when therapists or MH agencies report that they are unqualified to treat children/youth with co-morbid NDDs.

The trend of youth who self-refer.

1. Also, of late, youth self-referrals for autism are increasing. Youth who are struggling socially may need diagnostic assessments. Autism can be missed in early childhood, especially among girls, non-binary individuals and marginalized/minoritized communities. Yet, youth seeking particular "neuro-tribal" identification and who are not seeking services of any sort (a phenomenon we are seeing a lot lately) don't need the blessings of a developmental-behavioral diagnostician; they should just be their "neurodivergent" selves and enjoy the company of their neurodivergent friend-groups. If they don't want services, they don't need a diagnosis.

2. If they are experiencing emotional distress, they are better served by establishing a long-term therapeutic relationship with a counselor, so they can let down their guard (or "mask") and deeply engage in self-exploration rather than waiting greater than one year to meet with a stranger for a few hours for a one-off diagnostic assessment. Finally, it is important to note that a great many teens feel, at some point, that they are "weird"; we have to take care to avoid pathologizing adolescence.

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Autism Research

Summarized by Dr. Inge Hindel, FP consultant to OPAL

ASD is a neurological and developmental spectrum disorder that affects how people interact with others, communicate, learn and behave. There is no solitary cause of autism. The main contributor to autism is genetic (polygenetic). Large studies and meta-analyses have not shown any causative association with vaccines or vaccine preservatives such as thiomersal.

Summarized below are the most recent studies on autism as presented by the

NIH, alongside information from the National Institute of Environmental Health Sciences. The last review was conducted in December 2024, with the latest update on January 14, 2025.

Most studies collected in the references on the NIH site were done in the US, Sweden, and Finland. Several are large retrospective studies. A lot of data came out of the Childhood Autism Risk from Genetics and the Environment (CHARGE) study.

These studies show associations, and all authors call for further studies of possible mechanisms by which the associations could be contributing to brain development in the fetus or young child.

We do not have enough evidence to confidently advise prospective parents on specific factors to optimize the neurological development of their children at conception, and in utero. Maximizing the health, support, and nutrition of prospective parents and an environment low in toxins, will always be the best strategy to having children.

Based on specific studies to date, and with respect to autism related studies, **factors that might hold the biggest impact** for the prospective mother and family include:

1. Parental age at conception. Studies have consistently shown that paternal age over 45 years is correlated with a higher incidence of Autism Spectrum Disorder (ASD) diagnoses in children. Paternal age under 30 is associated with the lowest incidence (as much as a 6-fold risk difference). Mothers aged over 35 and under 20 have the highest incidence of having a child with ASD.
2. Having already had one child diagnosed with autism spectrum disorder (ASD). The incidence of having another child with ASD is significantly higher than the general population, estimated to be around 18.7%. This is approximately seven times greater than the general population's incidence of about 1.7%.
3. Avoidance of all alcohol in pregnancy.
4. Reducing obesity, hypertension, and high blood sugar levels before conception and during pregnancy.
5. Taking PNV with folic acid 3 months prior to conception and for the duration of the pregnancy.
6. Avoiding or treating fevers in pregnancy.
7. Avoiding pesticide exposures.
8. Avoiding air pollution, especially from vehicle exhausts and diesel.
9. Listed here are points sourced from the NIH site:

Research has identified various **environmental factors** that may contribute to the development of autism. The most well-documented evidence relates to events

occurring before and during birth, such as:

- Advanced parental age at time of conception.
- Prenatal exposure to air pollution or certain pesticides.
- Maternal obesity, diabetes, or immune system disorders.
- Extreme prematurity or very low birth weight.
- Any birth difficulty leading to periods of oxygen deprivation to the baby's brain.

These factors alone are unlikely to cause autism. Rather, they appear to increase a child's likelihood for developing autism (and other neurodevelopmental atypia) when combined with genetic factors.

Air pollution. Researchers found early-life exposure to air pollution may be a risk factor for autism.

- Children of mothers living near a freeway and traffic-related pollution during the third trimester of pregnancy were twice as likely to develop ASD. A distance of 1,014 feet, just under 3.5 football fields, was considered close to a freeway.
- Children with a mutation in a gene called MET, combined with high levels of exposure to air pollution, may have increased risk.

Prenatal conditions and maternal factors. Problems with a mother's immune system, certain metabolic conditions, or inflammation during pregnancy may be linked with higher rates of autism diagnosis for her children.

- Some mothers of autistic children have antibodies that may interfere with their children's brain development, possibly leading to autism.
- Maternal diabetes or obesity are linked to increased likelihood of having a child with autism or other developmental disability.
- Fever during pregnancy was associated with increased autism in offspring.

Metals, pesticides, and other contaminants. Prenatal and early childhood exposure to heavy metals, like mercury, lead, or arsenic; altered levels of essential metals like zinc or manganese; pesticides; and other contaminants cause concern.

- Researchers found that after adjusting for dietary and other mercury sources, children with autism had similar mercury levels in blood as those without.
- A study of twins used baby teeth to determine and compare levels of lead, manganese, and zinc in children with autism to their twin without the condition. Autistic children had lower levels of essential metals,

manganese and zinc, but had higher levels of lead, a harmful metal during specific developmental time periods studied.

- Researchers discovered that zinc-copper cycles, which control metal metabolism, are disrupted in individuals with ASD compared to their non-ASD twins.
- Maternal exposure to the insecticide DDT during early pregnancy was associated with higher risk of autism in their children.
- Researchers are also studying contaminants such as Bisphenol A, phthalates, flame retardants, and polychlorinated biphenyls to see if they affect early brain development and possibly play a role in autism.

Nutrition. NIEHS-funded studies have found taking prenatal vitamins may help lower autism likelihood of autism diagnosis. Furthermore, research suggests taking vitamins and supplements might provide protective effects for those exposed to certain environmental contaminants during pregnancy.

- Women were less likely to have a child with autism if they took a daily prenatal vitamin during the three months before and first month of pregnancy, compared to women not taking vitamins. This finding was more evident in women and children with genetic variants that made them more susceptible to developing autism.
- Folic acid is a source of the protective effects of prenatal vitamins. Women who took the daily recommended dosage during the first month of pregnancy had a reduced likelihood of having a child with autism.
- Folic acid intake during early pregnancy may reduce the impact on autism diagnosis of high exposure to air pollution15, and pesticides during pregnancy.
- Pregnant mothers who used multivitamins, with or without additional iron or folic acid, were less likely to have a child with autism and intellectual disability.
- Maternal prenatal vitamin intake during the first month of pregnancy may also reduce ASD recurrence in siblings of children with ASD.

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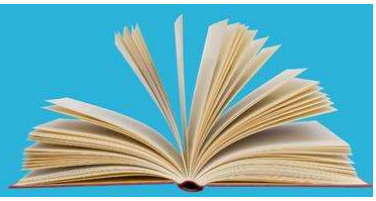

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