

MaineHealth

Stop Using That Word!: Navigating Early Child Autism Diagnoses in New Mainers

Grace Lapika, Community Health Worker

**Devon Stockmayer, Early Childhood Support
Specialist**

April 23, 2024

Neurodevelopmental Disorders



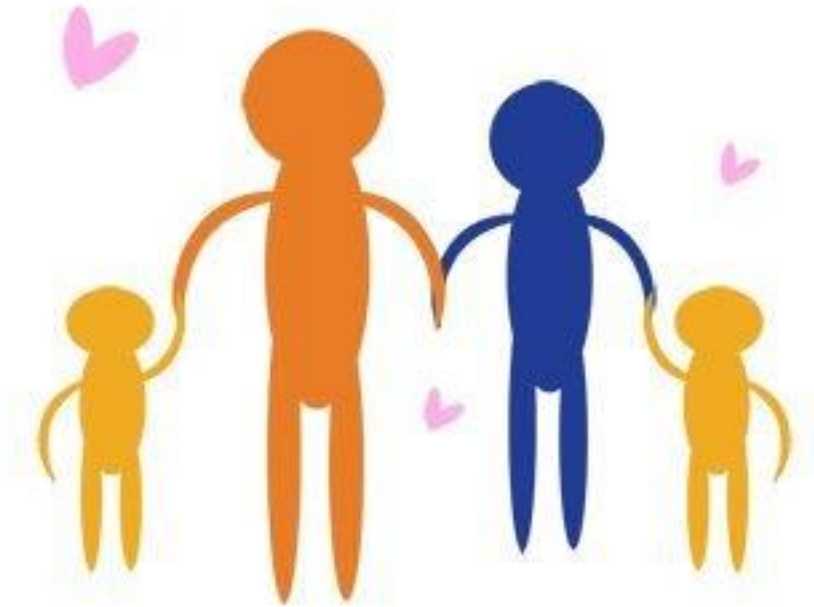
- Many neurodevelopmental disorders, such as Autism and Down Syndrome
 - Autism Spectrum Disorder (ASD): a neurodevelopmental (neurological + developmental) disorder that impacts the way people behave, communicate, learn, and interact with others. It is characterized by patterns of restrictive and repetitive behaviors. The disorder is a spectrum, as symptoms/presentation can range in severity from person to person.
 - Usually diagnosed between ages 2-5, signs can be sign as early as 12-18 mos.
 - Down Syndrome or Trisomy 21 is a genetic disorder caused by a full or partial extra copy of chromosome 21. It causes mild to moderate developmental changes and intellectual impairment and has hallmark physical features.

“Stop using that word!”

- CHW met with a family whose baby was in the NICU due to low birth weight (LBW), cardiac issues, and Down Syndrome
 - Family meeting held to review baby’s diagnoses and need for staying in the hospital until baby was appropriate for discharge
 - Social worker, physician, DHHS caseworker, and CHW
 - CHW communicated to care team that parents did not want to “hear” the word “Down Syndrome”
 - CHW educated parents on current and future care plan
 - DHHS involvement due to parents not adhering to the care plan
 - CHW remains involved to help adhere to care plan and navigating healthcare system

Addressing Family Concerns

- Community, family and clinical acceptance
- Cultural differences
- Beliefs:
 - Having Medicaid or FreeCare
 - "Witches"
 - Myths
- Complex healthcare system
- Lack of education or awareness



Recommendations to Address Misinformation & Stigma

- CHWs continue to connect with family and care team consistently
 - CHWs already check in with family weekly and share concerns with providers via confidential messages
 - CHWs provide bi-directional communication (care team and family)
- Continue to partner with CBOs
- Educate families on clinical terms they might hear often once child has official diagnosis
- Open dialogue with providers about what diagnostic language families are comfortable with
- Support must be tailored to voiced community needs

Educating families

- Early childhood screenings during well visits
 - Connecting with early childhood support specialist

Child Development Services: Who are they and what can they do to support your child?
- Appropriate care for family and child
 - Navigating healthcare system
 - Multiple pathways to the same support and interventions, Ex: CDS vs. Section 28, Behavioral/Developmental Pediatrics
- Parenting classes
- Provide culturally appropriate education
 - Signs in children
 - Emphasizing importance of appointments and reporting new signs and symptoms to providers
- Addressing myths

Next Steps

- Create culturally and linguistically appropriate educational material
- Create list of terms that would be acceptable/not acceptable
- Create support groups for families to attend: breaking down stigma, building trust
- Continue to collaborate with service providers and CBOs and educate
- Community outreach to breakdown stigma and raise awareness



WHO

WHEN

WHERE

HOW

WHY

WHAT

Questions?

Grace.lapika@mainehealth.org

devon.stockmayer@mainehealth.org