

Factors motivating rural caretakers to seek behavioral testing for children showing signs of autism

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Poster number

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Introduction

Autism spectrum disorder (ASD):

- ASD is a developmental disability caused by neurological differences.
- Currently, 1 in 44 children meet the diagnostic criteria for ASD.
- ASD diagnosis is based on:
- 1. Deficits in social communication
- 2. Restricted/repetitive behaviors
- 3. Early emergence of symptoms
- 4. Symptoms impair daily functioning
- 5. Not attributable to intellectual impairment

Diagnosing ASD:

- ASD is behaviorally diagnosed.
- Typically diagnosed using behavioral assays (CARS2, ADOS, etc...).
- Reliable ASD diagnosis possible at 18-24 months, but average age at time of diagnosis is 4.5 years (nationally).

Pitfalls of healthcare in rural areas:

- Missed doctors appointments
- Poor healthcare education
- Lack of specialists
- Logistical challenges
- Poor insurance

Challenges specific to diagnosing ASD in rural areas:

- 1. Inconsistently performed developmental screening
- 2. Lack of ASD awareness
- 3. Hesitancy among doctors to diagnose young children
- 4. Social stigma

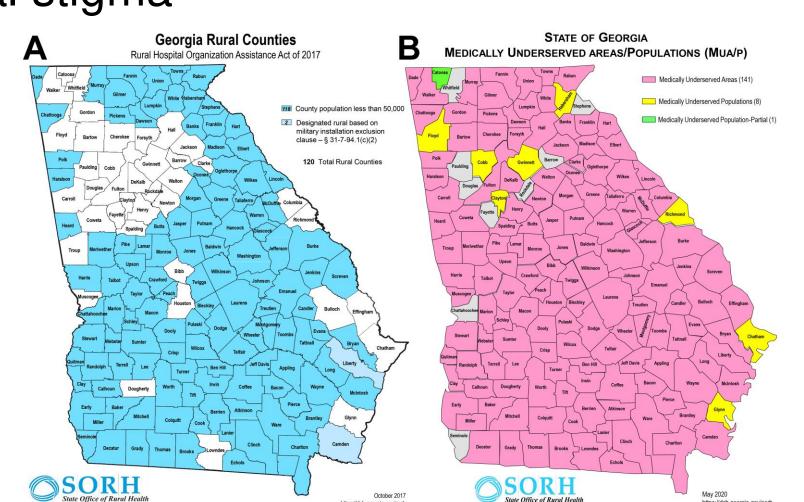


Figure 1: Rural and medically underserved counties in Georgia. 120 of Georgia's 159 counties are rural (A, blue) and 141 counties are medically underserved (B, pink).

Objectives

- 1. Identify which ASD symptoms are more obvious to caretakers.
- 2. Determine if certain symptoms are more obvious to rural or sub/urban caretakers.
- 3. Incorporate findings into our "Autism Spectrum Disorder Resources in Georgia" webpage.

Methods

Compare factors motivating caretakers to seek out behavioral testing

- Partnered with Dr. Michelle Zeanah (Behavioral Pediatrics of Rural Georgia, Statesboro GA).
- Evaluated 200 Valant EHR intake forms from children ultimately diagnosed with ASD. (Figure 2)
- o 76.5% boys, 23.5% girls
- 66.5% sub/urban, 33.5% rural
- Compared rural and sub/urban children for:
 - 1. Signs of ASD demonstrated
 - 2. Follow up care suggested by primary care physicians
 - 3. The referral process caretakers followed

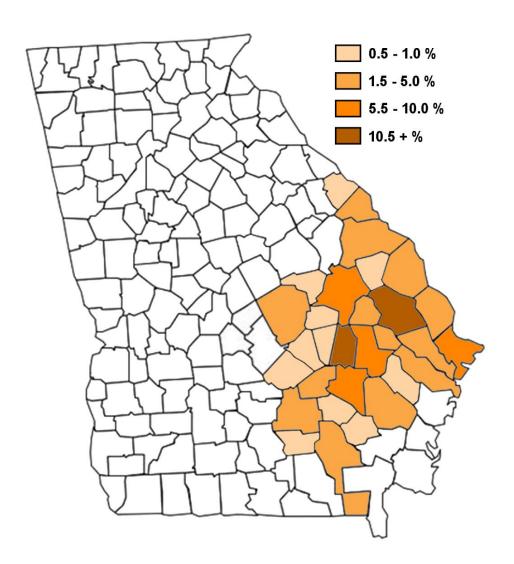


Figure 2: Counties of residence of children surveyed. Intake forms were reviewed for children diagnosed with ASD from 30 counties in southeastern Georgia. Participants form both rural and sub/urban zip codes were included.

Created webpage highlighting ASD resources in Georgia

- Assumed the perspective of a caretaker living in rural Georgia who had concerns about their child.
- Developed an interactive resource map showing the locations of ASD resources in Georgia.
- Developed a list of targeted ASD topics; included information about ASD on-boarding and ASD lifestyle topics

Results

Rural and urban caretaker report different signs of ASD

1. Rural and sub/urban caretakers reported certain sensory-motor skills with greater frequency:

Sensory-Motor Skills	All (%)	Rural (%)	Urban (%)	p-value
Problems managing their personal space	41.2%	53.3%	34.9%	0.042
Trouble using both hands together	24.4%	35.6%	18.6%	0.032
Picky eater	63.4%	77.8%	55.8%	0.013
Talks excessively	31.3%	20.0	37.2%	0.044

Table 1: Differences in sensory-motor skills reported by rural and urban caretakers.

2. Behavioral Testing and Follow-Up Care

Follow Up Care Suggested by Physicians	All (%)	Rural (%)	Urban (%)	p-value
Attend speech or occupational therapy	48.4	62.2	39.3	0.031
Babies Can't Wait	22.6	10.8	30.4	0.022
Head Start	3.2	5.4	1.8	0.334
Attend School or Day Care	39.8	35.1	42.9	0.457
Genetic Counseling	12.9	18.9	8.9	0.160

Table 2: Follow up care recommended by rural and urban primary care providers. Rural doctors were more likely to recommend speech or occupational therapy as follow up care and urban doctors were more likely to recommend Babies Can't Wait as follow up care.

3. Referrals and Behavioral Testing

- Rural caretakers were slightly more likely to self-refer $(\chi^2(1)=4.276, p=0.039)$.
- Referrals from primary care providers only accounted for 56.7% of referrals

Autism spectrum disorder resources in Georgia webpage

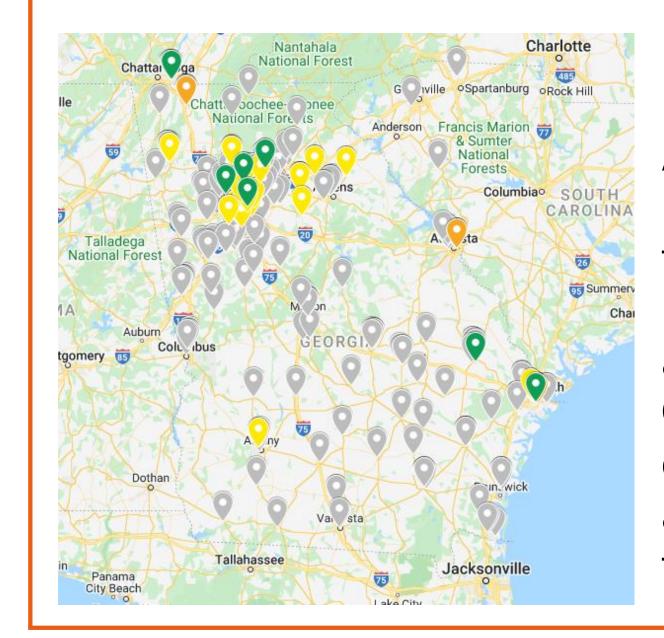


Figure 3: Interactive map of ASD resources in Georgia. We mapped resources for ASD testing, treatment, and lifestyle needs in the State of Georgia and listed them to our webpage. Our goal is to help families easily locate treatment options and sources of support within their home communities.

DOES MY CHILD HAVE A DEVELOPMENTAL DELAY?	- DOES MY CHILD HAVE A DEVELOPMENTAL DELAY?	- ASD FACT OR FICTION		
FINANCIAL INFORMATION AND SUPPORT	Children 1st	ASD Fact or Fiction!		
INFORMATION AND SUPPORT	This is your first stop for autism testing and resourcest. Children 1st is the single point of entry for all DPH Child Health programs and services for children, birth – 5 years old. All referrals made to DPH Child Health programs including Babies Can't Wait (BCW), Children's Medical Services (CMS), Early Hearing Detection and Intervention (EHDI), and 1st Care must be made through Children 1st.	There is a lot of information about ASD out there. Any Google search for ASD therapies or treatments will give you a nearly overwhen number of things to try that "parents awear by." But how do you know if they're safe? And, will those therapies actually work? Here evaluated how scientifically-backed some of the more popular hypotheses of ASD, diets for ASD, and non-medical ASD treatments v		
SOCIAL-EMOTIONAL DEVELOPMENTAL INFORMATION	To find a Children 1 st location that can assist you with on-boarding, follow the "Click here for the Children 1 st website" link listed below. Once you are on the Children 1 st website, click on the "Service Locator" tool (in a gray box that says "Look Up Your Local Coordinator" on the right side of the screen). To use the Service Locator tool, either enter your zip code or select your home county from the drop down menu. Check the Children 1 st click on the Search For Locations button. The addresses and locations of the nearest Children 1 st clinics should be listed	Do vaccines cause ASD?		
DEVELOPMENTAL INFORMATION	Unidren 1" Dox, then click on the Search For Locations button. The addresses and locations of the hearest Children 1" clinics should be listed under "Results."	Vaccines DO NOT cause Autism! There is no credible evidence to suggest that the MMR (measles, mumps, and rubella) vaccines		
UFALTI AND DISABILITIES	*Tip: If you do not see any results using the country drop down menu, search again using your zip code. Your nearest clinic may be outside of your home county.*	childhood vaccination causes autism. Multiple studies have been conducted concerning the safety of childhood vaccinations and autism, but no connection has been found.		
HEALTH AND DISABILITIES	Click here for the Children 1st website	 Do Preservatives in Vaccines Cause Autism? Since the Anti-Vaxx movement began, some have called into question the use of a mercury-containing preservative, in vaccines. After many studies concerning the safety of thimerosal, the scientific community 		
LITERACY AND LANGUAGE	Babies Can't Wait	that thimerosal is safe to use in vaccines and does not cause autism. Even though it is safe, thimerosal was removed or reduc- amounts from almost all childhood vaccines as a precaution.		
DENTAL RESOURCES	Georgia's Early Intervention program provides supports and resources for children (birth to age three) with significant developmental delays or qualifying medical conditions and their families. To apply for Babies Can't Wait services, please follow the Georgia Department of Public Health link below. Phone number: 888-651-8224	 What Started the Anti-Vaccination (Anti-Vax) Movement? In 1998, the former Dr. Andrew Wakefield published a paper where he claimed that the MMR vaccine may cause autism. Thus anti-vaxx movement. The original paper that began this movement was flawed. In fact, the publisher later redacted this paper. Wakefield's medical license was revoked as a result of the errors in this paper, and the scientific and medical communities rejclaims about vaccines. Since the late 1990's many studies have been conducted to determine whether or not there is a link be autism and vaccines and to confirm the safety of vaccines. 		
OLDER CHILDREN AND YOUNG ADULTS WITH ASD	Georgia Department of Public Health (Georgia DPH) Babies Can't Wait Program Brochure (available in English and Spanish) DPH Financial Guide for Babies Can't Wait Program			
ASD IN WOMEN AND GIRLS	Bright from the Start	You can read more about the history of vaccines and the history of the anti-vax movement here.		
CONSIDERATIONS FOR VISITING THE DOCTOR WITH AN AUTISTIC CHILD	 Georgia Department of Early Care and Learning offers support for inclusion through the inclusion Program with inclusion coordinators available in every community. These inclusion coordinators link families, childcare providers, and others to community resources to ensure that children are successfully included in early care and learning environments. www.decal.ga.gov 	Read more about the flaws of the Wakefield study in more detail here.		
ASD IN SOCIAL MEDIA	Centers for Disease Control	More Resources on Vaccines and Thirnerosal: Below is a list of scientific studies and resources that examined whether or not th link between autism and vaccines. The consistent conclusion was that there is no link between ASD and vaccines. * * Vaccines and Autism: A Tale of Shifting Hypotheses. This review was written to address three specific concerns that have been 1. Does the MMR vaccine cause autism? 2. Does thirmerosal, a preservative sometimes used in vaccines, cause autism? 3. Do vaccines simultaneously weaken a child's immune system?		
EARLY INTERVENTION THERAPY PRIMER	Tracking developmental milestones is an effective way of checking for developmental delays in young children and can be very helpful in detecting autism spectrum disorder early. The American Academy of Pediatrics recommends that doctors do developmental milestone testing for children at their 9 month, 18 month, and 30 month well-child visits, and that children should be specifically screened for autism spectrum disorder at 18 months and 24 months of age.			
TRANSPORTATION AND INFRASTRUCTURE FOR PEOPLE WITH ASD	To see if your child is meeting his or her developmental milestones, please follow the "Developmental Milestones (CDC)" link listed below. If you			
ASD FACT OR FICTION	would like to learn more about the signs of autism spectrum disorder, please follow the "Learn the Signs. Act Early (CDC)" Developmental Milestones (CDC) (PDF of checklist for 2, 4, 6, 9, 12, 18, 24, and 36 months) Learn the Signs, Act Early (CDC)	This paper looks at many different studies and determined that: 1. The MMR vaccine does not cause autism. 2. Thimerosal does not cause autism. 3. Giving multiple vaccines at once is safe and does not overwhelm or weaken the immune system.		
IMPROVING QUALITY OF LIFE FOR PEOPLE WITH AUTISM	Have an iPhone or Android? Download the Milestone Tracker App			

Figure 4: Topics listed on the Autism Spectrum Disorder Resources in Georgia webpage (A). Topics include information about on-boarding agencies (B), and also general ASD topics, such as ASD fact or fiction (C).



Figure 5: Autism spectrum disorder resources in Georgia QR code

Discussion

- There are unique challenges to diagnosing ASD in rural communities.
- Rural and urban caretakers differ in the signs and symptoms of ASD that they notice.
- Rural and urban primary care physicians differ in the follow up steps they recommend to their patients.
- The Autism Spectrum Disorder Resources in Georgia webpage offers families in rural areas information on resources in their area and on ASD topics.

References

Janvier YM, Harris JF, Coffieldd CN, Louis B, Xie M, Cidav Z, and Mandell D (2015). Screening for autism spectrum disorder in underserved communities: Early childcare providers as reporters. Autism. DOI: 10.1177/1362361315585055.

Antezana L, Scarpa A, Valdespino A, Albright J, and Richey JA (2017). Rural trends in diagnosis and services for autism spectrum disorder. Frontiers in Psychology. DOI: 10.3389/fpsyg.2017.00590.

Monz BU, Houghton R, Law K, and Loss G (2019). Treatment patterns in children with autism in the United States. Autism Research. DOI: 10.1002/aur.2070.

Sices L (2007). Developmental screening in primary care: the effectiveness of current practice and recommendations for improvement. The Commonwealth Fund.

Fountain C, King MD, and Bearman PS (2011). Age of diagnosis for autism: individual and community factors across 10 birth cohorts. J Epidemiol Community Health. DOR: 10.1136/jech.2009.104588.

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