



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

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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:
  - Deficits in social communication
  - Restricted/repetitive behaviors
  - Early emergence of symptoms
  - Symptoms impair daily functioning
  - Not attributable to intellectual impairment

### Diagnosing ASD:

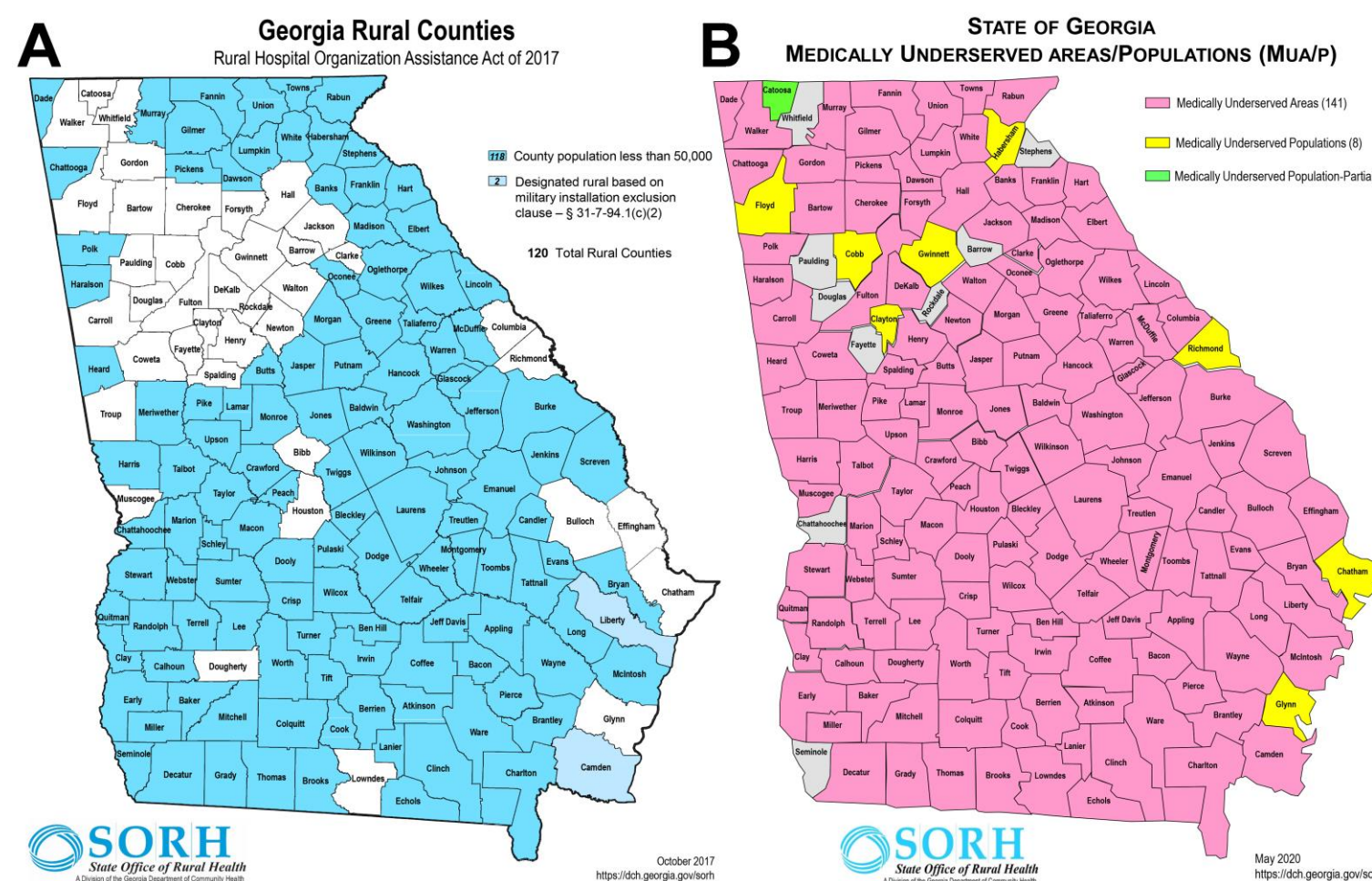
- ASD is behaviorally diagnosed.
- Typically diagnosed using behavioral assays (CARS2, ADOS, etc...).
- Reliable ASD diagnosis possible at 18-24 months, but average age at time of diagnosis is 4.5 years (nationally).

### 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:

- Inconsistently performed developmental screening
- Lack of ASD awareness
- Hesitancy among doctors to diagnose young children
- 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).

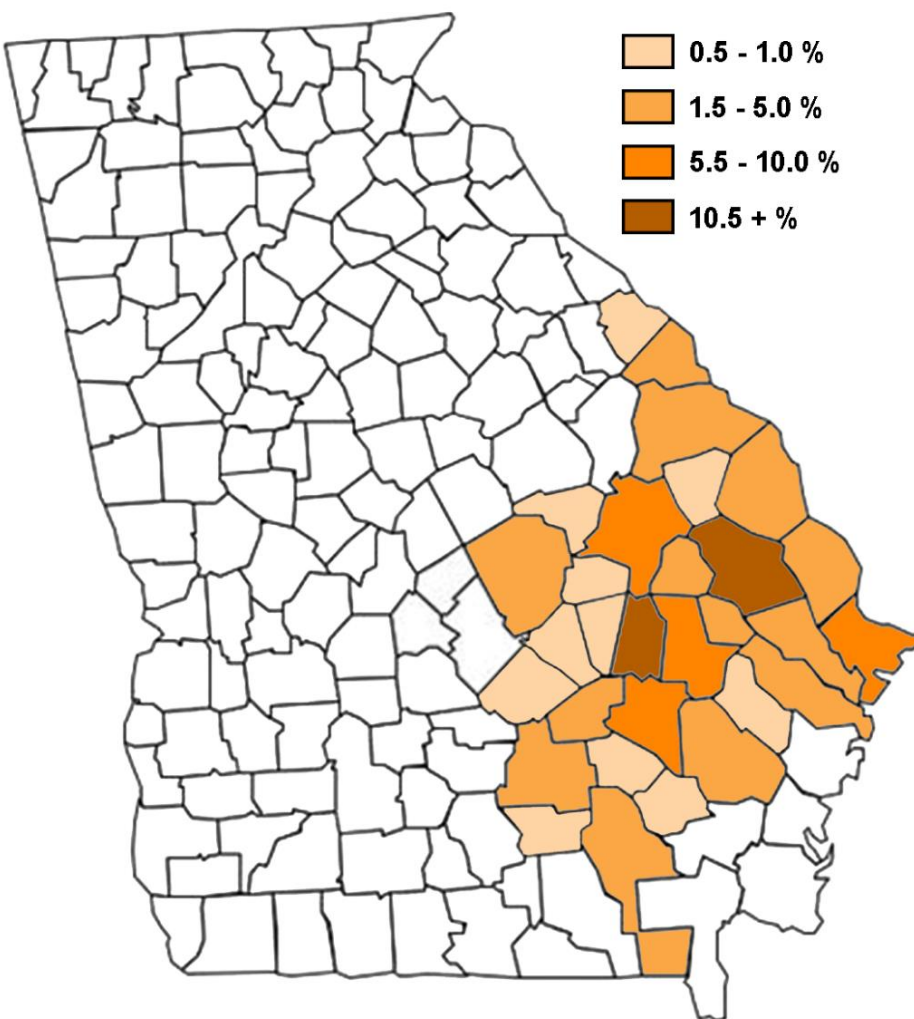
## Objectives

- Identify which ASD symptoms are more obvious to caretakers.
- Determine if certain symptoms are more obvious to rural or sub/urban caretakers.
- 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)
  - 76.5% boys, 23.5% girls
  - 66.5% sub/urban, 33.5% rural
- Compared rural and sub/urban children for:
  - Signs of ASD demonstrated
  - Follow up care suggested by primary care physicians
  - 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

- 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.

- Behavioral Testing and Follow-Up Care

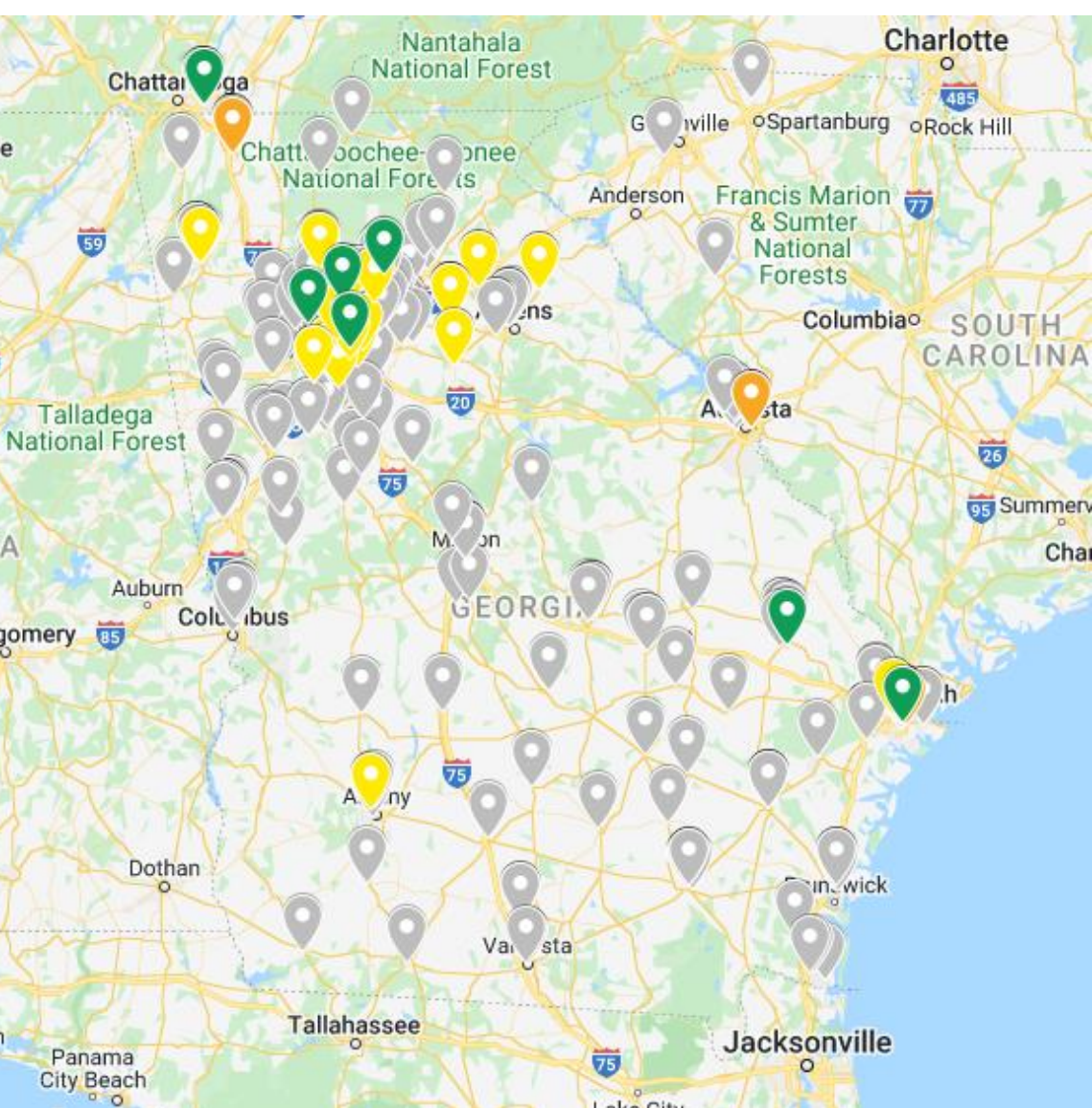
Follow Up Care Suggested by Physicians	All (%)	Rural (%)	Urban (%)	p-value
Attend speech or occupational therapy	48.4	62.2	39.3	0.031
Babies Can't Wait	22.6	10.8	30.4	0.022
Head Start	3.2	5.4	1.8	0.334
Attend School or Day Care	39.8	35.1	42.9	0.457
Genetic Counseling	12.9	18.9	8.9	0.160

**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.

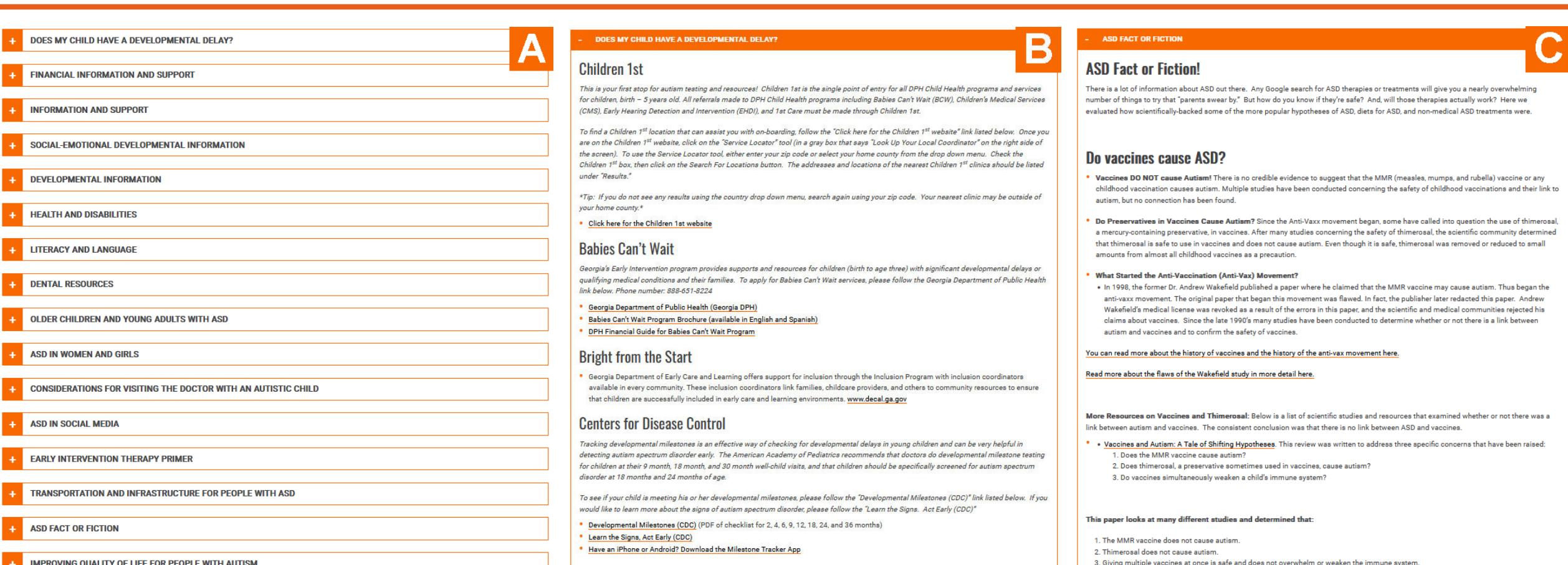
- Referrals and Behavioral Testing

- 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.



**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.

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