



Services for Children with ASD: Comparing Rural and Non-Rural Communities



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Abstract

This study examined the individual differences in access, recommendations, use, and effectiveness between rural and non-rural services for families of children with Autism Spectrum Disorders (ASD). The participants in this study were 426 caregivers of children with ASD up to 21 years of age, of which 101 lived in rural areas (23.7%). The participants completed an online survey and answered questions regarding access and quality of different services that children with ASD may use. Results suggest that for rural families behavior services at home and parent services (parent workshops, training, etc.) that are recommended by professionals may not be easily implemented due to lack of availability. In addition, a map was created using databases with locations of professionals for two services that are widely used by children with ASD, Applied Behavior Analysis (ABA) and Speech Language Pathology (SLPs). The map showed that almost all counties contained SLPs, however, very few had Board Certified Behavior Analysts (BCBAs). Furthermore the counties that did have BCBAs were mostly non-rural counties. These results show that for specific services in rural areas, families may have limited access and lower perceptions of service effectiveness.

Introduction

Across all types of disabilities, rural families may experience more difficulty accessing services. For example, rural parents report decreased access to services, and the services themselves are considered to be less effective (Mandell, et al, 2005; Chen, et al, 2007). Other studies have found that rural families have less access to specialized personnel and services, such as mental health services (Knapczyk, Chapman, Rodes, Chung, 2001; Murphy & Ruble, 2007; Hendryx, 2008). Murphy and Ruble (2012) found that parents in rural and non-rural areas expressed a higher need for social skills training, speech language therapy, and behavior management. Rural parents expressed an especially high need for behavior management (Murphy & Ruble, 2012). The ease of finding trained professionals and physicians was significantly lower for rural families.

To date, however, few studies examine the availability, quality, and effectiveness of individual services for children with ASD. This study looks at individual differences for services that children with ASD use and addresses the following questions :

Research Questions

- 1.Which services are recommended for and used by families and children with ASD, and to what degree is each service available (or not) in rural versus non-rural areas?
- 2.Do rural versus non-rural parents differ in their levels of satisfaction with the services that they receive, or in their respective perceptions of effectiveness of different services?
- 3.Using a map of Tennessee, how do services compare for more vs. less available services across rural and non-rural areas of the state?

Method

Procedures

Created to conduct a statewide resource mapping of services, this survey arose from the efforts of the TN Autism Summit Team, a group of community service providers, clinicians, and researchers working with children with ASD and their families. The goal was to assess the service needs for children with ASD in the state of TN.

Participants/Caregivers:

- 426 caregivers with a child with ASD
- Respondents were mostly:
 - mothers (90.8%)
 - White (83.7%)
 - married (76.0%)
 - bachelors degreee or more (57.9%)
- 66% of TN's 95 counties are represented
- 76.6% of respondents lived in non-rural areas.

Children with ASD :

- First-born boys with a mean age was 10.9 years (sd= 5.83).
- Usually diagnosed between the ages of 30-48 months (N=105) and above 72 months/6 years (N= 107).
- The age of first concern for the caregiver was between 0-24 months.

Survey:

- Approximately 80 questions long, 25-30 minutes to complete
- Both English and Spanish surveys available
- Participants must have had a child with ASD in order to complete survey , aged 21 or below.
- Voluntary and anonymous, available in paper or web based format
- Reviewed and approved by members of Autism Summit Team before opening online for 6 months on REDCap

Distribution:

- Flyers created in both English and Spanish, included the purpose and the web link
- Distributed through flyers, phone calls and emails to members of the TN Autism Summit Team, the three Autism Societies (East, Middle, and West), and 538 disability service organizations across the state.
- In addition, distributed through contacts and different city events.

Questionnaire:

- Consisted of four sections
- Section I: Basic Demographic information on Respondents
- Section II: Child Characteristics, including diagnosis, severity of behaviors and functional abilities
- Section III: Service satisfaction, importance, effectiveness, recommendations, distance, specific providers (name & location), for 13 different services (e.g. ABA, SLP, OT, PT, Special Education, etc.)
- Section IV: Service Coordination & Open Ended Questions

Open Ended Questions:

- Question: "What advice would you give to other parents about receiving and coordinating services in your area?"
- 58% (N=247) of participants responded to this question.
- Two individual researchers read the responses and collaborated to obtain five themes.

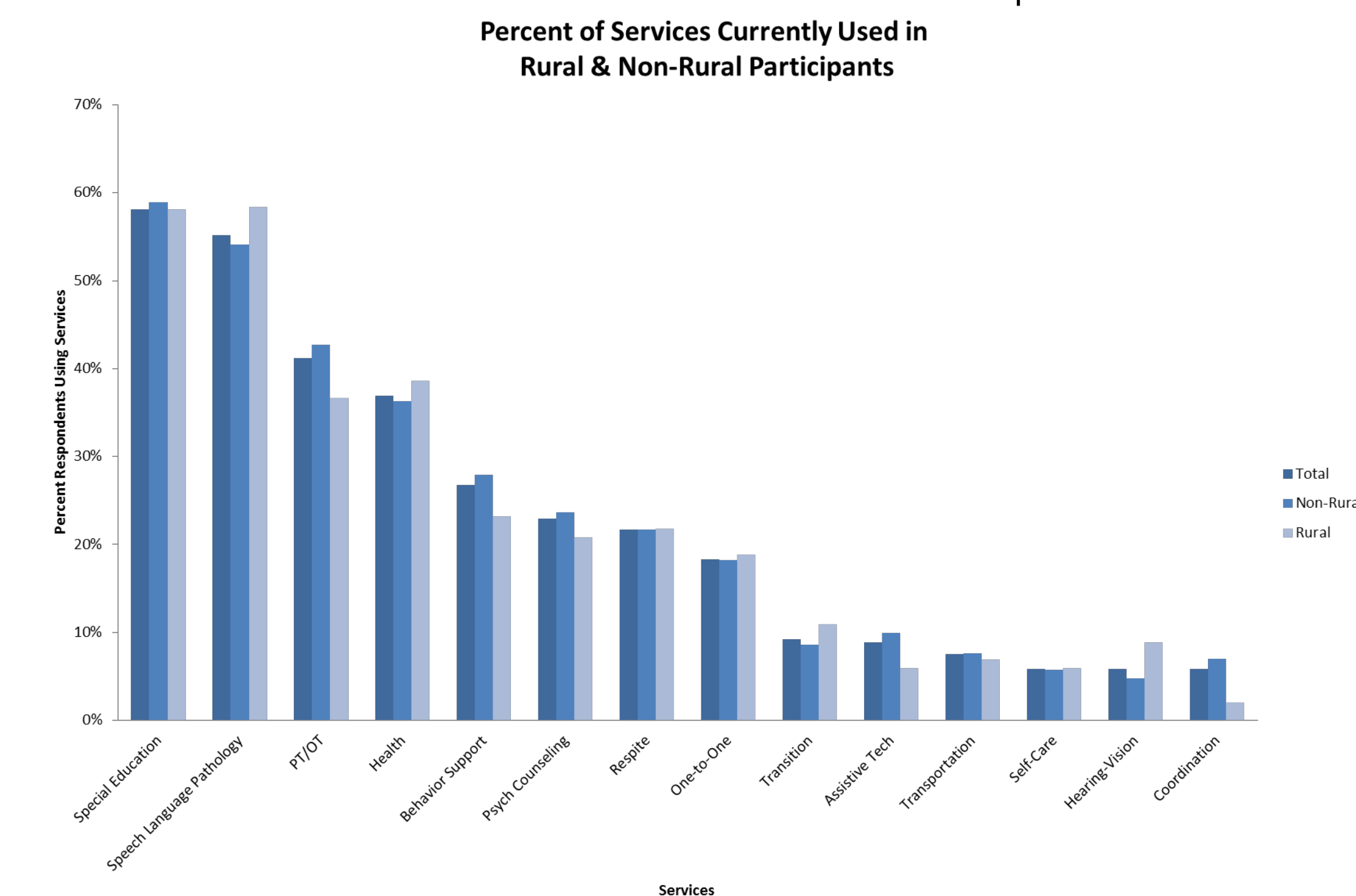
Maps:

A map of Tennessee was created with each individual county representing the presence of Speech Language Pathologists (SLP) and Board Certified Behavior Analysts (BCBAs). The data for BCBA location was obtained from the website: www.bacb.com . The data for SLPs was obtained from TN Department of Health website: <http://health.state.tn.us/boards/CD/>.

Results

Services Currently Used:

Parents were asked if they were currently receiving the service for 13 different services. For most services, families of children with ASD were more likely to use Special Education, SLP, PT/OT, health services, followed by behavior services. These rates were similar across non-rural and rural parents.



Recommended Services & Services Used:

Parents were asked if they were recommended for 19 different services. If they were recommended, were they able to implement that service.

- Rural parents were less likely to implement in-home behavior support services χ^2 (1, N= 31), 11.02 p<.001.
- Of the parent services, rural parents were less likely to implement parent workshops, parent support groups and talking to other parents than non-rural parents

Effectiveness of Services:

- Parents were asked if 10 different services were effective for their child.
- Rural parents were more likely to rate ABA as less effective than non-rural parents, $t(37)= 3.99$, p<.001.
- Rural parents were also more likely to rate parent workshops as less effective than non-rural parents, $t(52)= 2.30$, p<.02

Table 1 Services Recommended Currently Received

	Non-Rural (N)	Rural (N)	χ^2	p
Parent Related Services				
Parent Workshop	78.5% (106)	56.7% (17)	6.18	.013*
Parent Support Group	64.3% (101)	38.6% (17)	9.36	.002*
Talk to other parents	90.4% (113)	75.9% (22)	4.60	.032*

Table 2 Effectiveness of Services

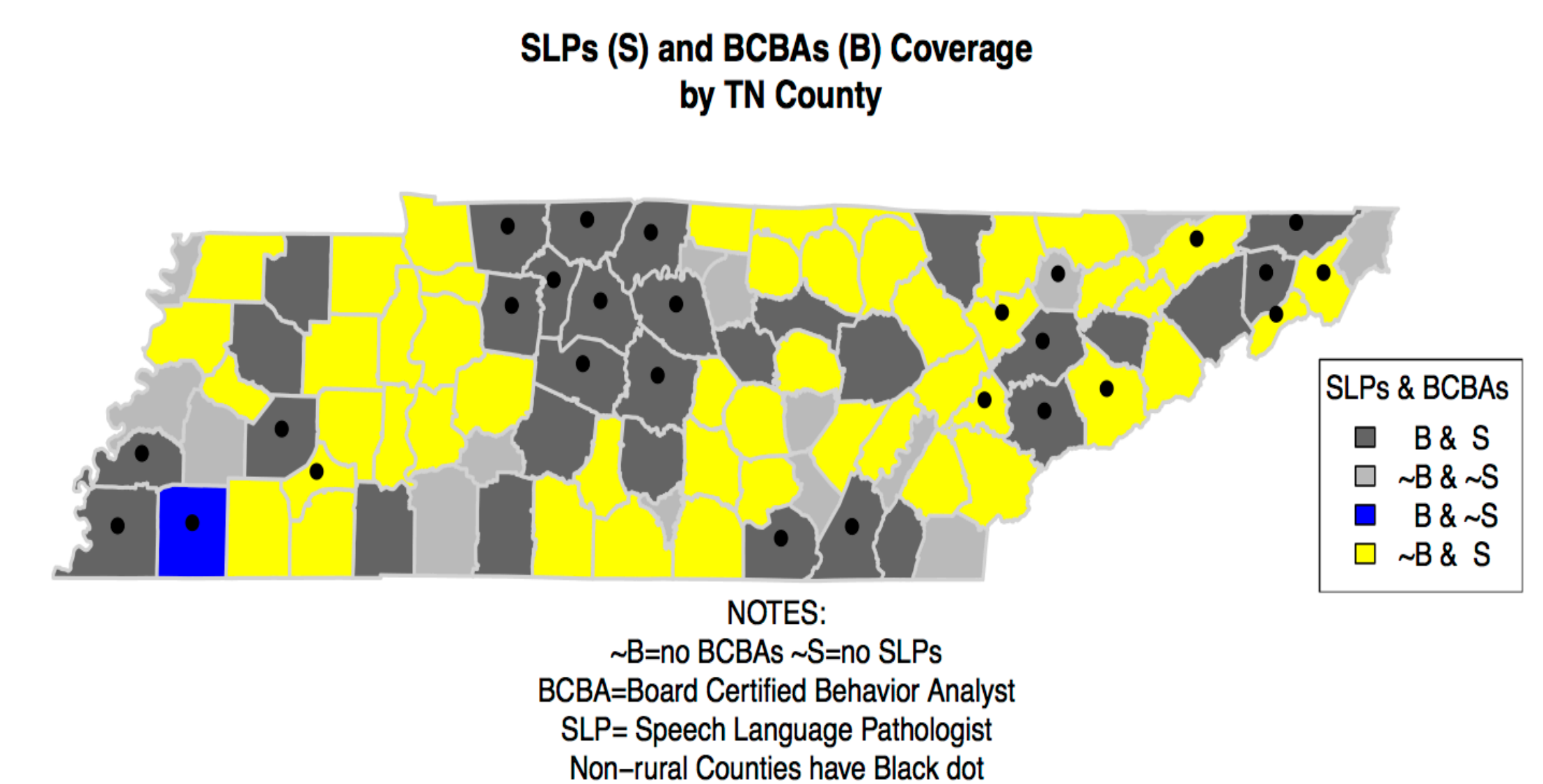
Effectiveness	Non-Rural (sd)(N)	Rural (sd)(N)	t	p
ABA	3.85 (1.17) (134)	2.95 (1.37) (37)	3.99	.001*
Parent Training Workshop	3.44 (1.15) (210)	3.02 (1.37) (52)	2.30	.022*

Results

Maps:

We created a map of locations of certified SLPs and BCBAs in the state of Tennessee and indicated whether the county was rural and non-rural.

- Yellow counties (SLP & no BCBA) consisted of a majority of the counties, 48 of the 95 counties (50.5%).
- The dark gray counties (BCBAs & SLPs), consisted of 32 of the 95 counties (33.68%). It is important to note that the counties that have both BCBAs and SLPs were mostly the non-rural counties (18 out of the 27 non-rural counties).
- The light gray counties (neither BCBA or an SLP) consisted of 15 counties (15.8%). Only one county had a BCBA and no SLP (1.1%).



Open Ended Question:

- (1)self-reliance: relying on oneself to get information or services (kappa= .807),
- (2)seek outside help: reaching out to someone else for information or services (kappa= .775),
- (3) coordination of multiple services: process of coordinating services (kappa= .844),
- (4)limited services in specific areas: geographic location with lack of services (kappa= .924)

- Between rural and non-rural respondents, for the open-ended questions, rural respondents were more likely to state that there was limited service in their specific area, χ^2 (1, N= 25), p<.003 .

Conclusions

In general, many services seem to be equally available to both non-rural and rural families with children with ASD. However, parent services and behavior services, were considered less available and less effective by the parents in rural areas than parents in non-rural areas. This is corroborated by the map that highlights there are fewer BCBAs available than SLPs, two services that are widely used by children with ASD. Furthermore, BCBAs tend to be in non-rural counties, whereas SLPs are in almost every county.

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