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Therapy Needs for Children with Autism in a Rural, Under-served Island Community

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Abstract

Specialized care is essential for children with autism spectrum disorders (ASD), but adequate access to such care is often limited in rural areas. The Florida Keys are a group of rural, medically underserved islands off the southern coast of Florida. This two-part study provides: (1) a workforce needs assessment for common therapies including: applied behavior analysis (ABA), occupational therapy (OT) and speech language pathology (SLP) services and (2) a focus group study of parents/caregivers' perspectives. Needs assessment estimates are based on population data and licensure/certification records and reveal a shortage of approximately 96 registered behavior technicians (RBTs), 27 BCBA/BCBA-Ds (according to the BACB tiered service model), 54 OTs and 25 SLPs. Eleven caregivers of children with ASD provide important insights regarding the lived experience of accessing local, specialized care. Caregivers describe their experiences and the negative impact of limited access to care, point to specific barriers that prevent adequate access to care, and identify primary concerns for children including social skills, emotional regulation, and behavior management. Possible solutions are discussed for local program development and future research.

Keywords: autism, rural, therapy, behavior, needs assessment

Public Health Significance Statement: This study suggests that there are significant gaps in common services (ABA, OT, and SLP) for children with autism spectrum disorder (ASD) in the rural, underserved area of the Florida Keys. Children with ASD require specialized care from multiple disciplines and inadequate access to care can have a direct negative impact on functional abilities as well as physical and mental health for both children with ASD and their families. Additionally, this study reflects on parents' qualitative feedback regarding limited access to care.

Introduction

Rural health disparities often arise from a triad of factors including geography, culture, and economy (Thomas et al., 2014; Bishop-Fitzpatrick & Kind, 2017; Dallman et al., 2020). The Florida Keys, located in Monroe County, are a geographically unique string of islands that have been designated as rural and medically underserved (Health Resources and Services Administration [HRSA], 2020). The islands are connected by 42 bridges along a single road that stretches 100 miles southwest from the southern tip of Florida. The island chain is divided into three regions: Upper, Middle and Lower Keys. As with other rural communities across Florida, families of children with special needs are often required to travel long distances to obtain services in the nearest major city on the mainland, Miami (Delmelle et al., 2013). For families in the Upper Keys, this means up to a 70-mile drive, while those in the Lower Keys and Key West may drive 150-miles or more to reach parts of Miami.

The unique geography of these islands makes this area in some ways more isolated than other rural areas in the United States. This isolation also impacts local culture and economy. The local culture can be described as unified, independent, and resilient. In 2001, Monroe County commissioners adopted the motto, “One Human Family” as the philosophy of the Florida Keys (Florida Keys and Key West, 2019). The slogan illustrates the strong sense of unity within the rural community but does not speak to the industrious and independent nature of the locals. The Florida Keys are also known as the “Conch Republic”. What began in 1982 as an attempt to secede as a new micronation, has become an everlasting identity for the Florida Keys people, often referred to as “Conchs” (Florida Historical Society, n.d.). Following the recent devastation of Hurricane Irma in 2017, locals banded together to repair homes and businesses and adopted the motto “Keys Strong” which became a successful local charity organization that continues to

focus on “community engagement and resiliency” (Keys Strong, n.d.). The local culture and economy are also influenced by and centered around outdoor, adventure and water-based activities such as fishing and scuba diving as well as eco-tourism, attracting a workforce and businesses focused primarily on these activities and less so on other industries such as healthcare.

According to the 2018 Census, the Florida Keys are home to 75,027 people, of which 11,329 are children (United States Census Bureau, 2019). Considering that 1 in 54 children have autism spectrum disorder (ASD) (Centers for Disease Control and Prevention [CDC], 2018), it is estimated that approximately 210 children in Monroe County, Florida are currently living with ASD. For children with ASD, long standing evidence supports that adequate access to early interventions is essential and results in improved function and social engagement (Case-Smith & Arbesman, 2008). Evidence-based practices for children with ASD (Wong et al., 2015) are commonly provided by allied health professions such as applied behavior analysis (ABA), occupational therapy (OT) and speech therapy (i.e., speech language pathology SLP). The amount of therapy required to treat children with ASD varies depending on the type of therapy as well as the severity of ASD and individual client needs.

In general, research has demonstrated that ABA is a highly effective treatment for children with ASD (Reichow, 2012; Wong et al., 2015) and involves techniques used to facilitate desired learning and behavior (Simpson, 2001). Although 10-25 hours of ABA per week is most common, children with ASD who have severe problem behaviors may benefit from 30-40 hours per week (The Council of Autism Service [CASP], 2020). Occupational Therapy focuses on evaluating children’s performance and developing interventions to improve quality of life and engagement in daily activities (Case-Smith & O’Brien, 2014). Sensory-based OT for at least 2

hours/week can lead to improvements in stereotypical behaviors, self-regulation, social-emotional function and fine motor skills (Simpson, 2001). Approximately 98% of occupational therapists report using sensory-based approaches with children who have ASD (Thompson-Hodgetts & Magill-Evans, 2018). Speech Language Pathology focuses on promoting social communication skills as well as preventing, assessing, and treating speech disorders in children (American Speech-Language-Hearing Association [ASHA], n.d.). At least 1 hour of SLP per week can improve peer interaction skills (Goldstein, 2002) and social-communicative behaviors (Rogers et al., 2006). Research also overwhelmingly suggests that multi-disciplinary and comprehensive intervention targeting behavior, social and communication skills in early development can have a significant impact on later cognitive and academic functioning (Reichow & Wolery, 2009). Thus, to ensure that children achieve the best outcomes and quality of life possible, it is necessary to be proactive in identifying and remediating any gaps in access to care.

The aim of the present study is two-fold: (1) to conduct an estimated needs assessment of pediatric therapy services in Monroe County, Florida and (2) to explore the perceptions of parents with ASD regarding therapy services and access to care. The ASD population was chosen for this assessment for the following reasons: (1) there are clear prevalence estimates and treatment frequency guidelines that are useful for establishing estimates of need, (2) there is a well-organized support network of parents in Monroe County making it feasible to interview a group of parents with specific needs and (3) children with ASD often require several types of therapy services; thus, this population can be used as a “litmus test” for identifying pediatric service gaps in this rural community.

Methods

Needs Assessment for Pediatric Services in Monroe County

The needs for specialized pediatric services in Monroe County were estimated in a three-step process. First, researchers gathered data regarding the actual number of ABA, OT and SLP therapists available in the county using licensure records. Information was also collected regarding the number of assistant certifications for each field such as board-certified assistant behavior analysts (BCaBAs) and registered behavior technicians (RBTs) in ABA, certified occupational therapy assistants (COTAs) in OT, and speech language pathology assistants (SLPAs) in SLP. However, it should be noted that the needs assessment calculations were not based on these assistant roles due to their inability to practice independently. Null and void, as well as retired licensees were also omitted from the results. Second, the actual number of therapists was converted to the actual number of therapy hours available for children with ASD per week. Third, the actual number of therapists and therapy hours were compared to the expected number of therapy hours required to serve 210 children with ASD. Since it is unrealistic to assume that all of the providers identified would have caseloads filled only with children with ASD, it was conservatively assumed that providers working in Monroe County must serve diverse populations of pediatric diagnoses. Therefore, caseload demographic data and guidelines were used to calculate estimates of ASD within each profession. The specific data and guidelines are presented for each profession in the sections that follow.

Applied Behavior Analysis (ABA)

A certification registry search provided the actual number of board-certified behavior analysts (BCBAs), board-certified behavior analyst doctorates (BCBA-Ds), board-certified assistant behavior analysts (BCaBAs) and registered behavior technicians (RBTs) who are currently registered (as active) within Monroe county (Behavior Analyst Certification Board

[BACB], 2020a). According to ABA practice guidelines, children with ASD typically receive 10-25 hours of ABA per week, but may benefit from as much as 30-40 hours per week for more severe cases (CASP, 2020). For the purpose of this study, estimates of need were conservatively based on a minimum of 10 hours of ABA per week per child. In order to estimate actual ABA services available, it is important to understand the tiered service model typically used (Board, B.A.C., 2004). In this tiered model, case managers or supervisors (BCBA or BCBA-D) provide at least 2 hours of supervision for every 10 hours of service provided by an RBT (CASP, 2020). BCaBAs can provide additional supplemental supervision that may incrementally increase the number of RBTs providing services. According to practice guidelines, case managers (BCBA/BCBA-D/BCaBA) are expected to spend approximately 50% of their time or 20 hours/week providing or supervising direct care services (i.e., 50% of a 40-hour work week) (BACB, 2020b); whereas, RBTs are expected to spend 100% of their time providing direct care (CASP, 2020). Although it is possible for an ABA caseload to be 100% focused on ASD alone, in a rural, underserved area where providers may have to serve as generalists seeing all diagnoses, it is conservatively estimated that ABA therapists in this area would be able to focus 50% of their caseload on ASD. Thus, those certified for case management such as BCBA/BCBA-D/BCaBA can provide 10 hours/week of ABA serving one child with ASD per week; whereas RBTs can provide 20 hours/week of ABA serving up to two children with ASD per week.

Occupational Therapy (OT)

Licensure records were used to identify the actual number of occupational therapists (OTs) and certified OT assistants (COTAs) with current, active licenses in Monroe county (Florida Department of Health [DOH], 2020). According to practice data, OTs typically spend

60-70% of their working hours in direct patient care (American Occupational Therapy Association [AOTA], n.d.), indicating a maximum of 28 hours/week available per therapist for direct care (i.e., 70% of a 40-hour work week). It is unclear what the typical OT pediatric caseload demographics are in the United States; however, in Australia the majority of OTs report that 25% or more of their caseload has been diagnosed with ASD (Ashburner et al., 2014). Based on this report, we conservatively estimate each OT to have at least 7 hours/week (i.e., 25% of 28 hours) available to treat children with ASD.

Speech Language Pathology (SLP)

Licensure records were also used to identify the number of SLPs and SLP assistants (SLPAs) with current, active licenses in Monroe county (DOH, 2020). According to SLP practice surveys, SLPs typically spend approximately 80% of their total work time in direct patient care (ASHA, 2017), indicating a maximum of 32 hours/week of direct patient care (i.e., 80% of 40 hours). Considering that children with ASD make up approximately 10-20% of pediatric SLP treatment time across various settings (ASHA, 2017), we conservatively estimate that SLPs each have approximately 6.4 hours/week (i.e., 20% of 32 hours) available for working with children with ASD specifically.

Parent Perspectives of Therapy Services in Monroe County

A phenomenological approach was used to gain a better understanding of the lived experiences of parents of children with ASD when accessing services in Monroe County. For this approach, a face-to-face semi-structured group interview was conducted in the form of a focus group during a local parent support group meeting. The interview questions were used to provide structure, while still allowing for flexibility in discussion. Five broad, open-ended questions were used to generate discussion regarding the research aims (Table 1) and to better

understand parent's subjective experiences, perspectives, thoughts and feelings regarding accessing local care. In preparation for the focus group, study procedures were piloted with a small group ($n = 5$) of occupational therapy graduate students and faculty to assess clarity and validity of the structured interview questions. To ensure a genuine and detailed understanding of the study's targeted population a purposeful sampling method was used for recruitment procedures. This sample of convenience included parents of children with ASD living in Monroe County, Florida. Prior to the study, approval was granted by the institutional review board. Participants and caregivers at least 18 and older who have children ages 0-21 with ASD were invited to participate through a small (~20 member) local parent support group on social media. Informed consent was obtained prior to participation, as approved by the ethical review committee [blinded for peer review]. Eleven parents and caregivers from the parent support group (hereto after referred to as "parents") agreed to participate in the focus group study. All participants were female and ranged in age from 35 to 50 years. Digital tape recordings and field notes were used for data collection. Audio recordings were transcribed, and cross checked with field notes. All transcripts were then de-identified and audio recordings were later deleted to ensure privacy.

Data Analysis. Transcripts were coded by three researchers using the constant comparative method (Ryan et al., 2016). A code dictionary was created using coding software (NVivo 11 by QSR International). Researchers reviewed and refined codes until consensus was achieved among the codes and thematic content. After cohesive analysis and final consensus was achieved, common themes were identified and summarized to express the true nature of the content discussed in the focus group.

Results

Needs Assessment Estimates for Pediatric Services in Monroe County***Applied Behavior Analysis (ABA)***

There are 13 BCBA/BCBA-Ds, 2 BCaBAs and 9 RBTs active and registered throughout Monroe county (Table 2) (BACB, 2020a). Based on these estimates, ABA represents the largest service gap in this study. If children with ASD benefit from 10 hours/week of ABA on average, 210 children with ASD would require 2,100 hours per week of ABA services total, which would require 195 BCBA/BCBA-D therapists, if working alone (Table 3). However, since a tiered service model is considered standard practice according to the Behavior Analysis Certification Board (BACB) guidelines for ASD treatment (CASP, 2020), the estimated ABA needs would be best met by having at least 27 BCBA/BCBA-Ds providing supervision to 96 RBTs providing ABA treatment (Table 4).

Occupational Therapy (OT)

There are approximately 22 licensed and registered occupational therapists (OTRs) and 6 certified occupational therapy assistants (COTAs) in Monroe county (Table 2) (DOH, 2020). According to the American Occupational Therapy Association's 2015 Salary and Workforce survey, 20-25% of OTRs practice in pediatric settings including early intervention and schools (AOTA, n.d.). Thus, it is estimated that there are approximately 6 OTRs in Monroe county working with children (i.e., 25% of the 22 OTRs). If 210 children with ASD require 2 hours/week of OT each, they would collectively require 420 hours/week of OT. After comparing estimates of OT therapy needs vs. hours of therapy available to children with ASD, there is a shortage of approximately 378 hours of OT that would require an additional 54 OTRs (Table 3).

Speech and Language Pathology (SLP)

There are 19 licensed SLPs and 1 SLPA in Monroe county (Table 2) (DOH, 2020). According to ASHA, 40% of SLPs spend their clinical service time working with children (ASHA, 2017), it is estimated that 8 SLPs currently work with children (i.e., 40% of the 19 SLPs). If 210 children with ASD require 1 hour/week of SLP, collectively they would require 210 hours of SLP services per week. After comparing estimates of SLP therapy needs vs. hours of SLP therapy available to children with ASD, there is a shortage of approximately 159 hours a week of SLP services that would require an additional 25 SLPs (Table 3).

Parent Perspectives of Therapy Services in Monroe County

Ten mothers and one grandmother of children with ASD shared personal experiences when seeking and utilizing local therapy services in Monroe County. Their discussion revealed common themes illustrating inadequate access to specialized care and identifying potential explanations for limited services in this area. The common concerns regarding ASD symptoms included: (1) social skills, (2) maladaptive behaviors and (3) emotional regulation. The common themes that emerged from the discussion are reported below with supporting quotations from participants.

Theme 1: Social Skills. Nine participants (81%) reported limitations in social interactions and situations as a primary concern for their child. Several parents agreed they are afraid that their child *will not be able to form long lasting relationships (P01)*. Participants mentioned that their child *was not interested in interacting with their peers (P03)*. When speaking about deficits in social skills, parents also described their child's inability to follow social norms and maintain conversations. These participant responses placed great emphasis on the importance of their child's social skill development and the need for sufficient provision of services in this area.

Theme 2: Maladaptive Behaviors. Four participants (36%) reported concerns regarding behavior issues. Although this is proportionally less than social skills, those who reported concerns with behavior, reported serious concern in this area. One participant explained her biggest concern is behavior describing that *even if it's something that he wants to do, his automatic response is 'no' (P01)*. She further mentioned that these behaviors significantly impact his academic performance and engagement in social participation. Another participant describes, that *when regular kids are around her, she gets aggravated quite easily and then she reacts to situations very quickly and that's where the behavior happens. She will go into pushing somebody... (P09)*.

Theme 3: Emotions. Approximately four participants (36%) reported emotional regulation concerns, which was often mentioned in-conjunction with other skills. For example, emotions often lead to maladaptive behaviors or are exacerbated by social interactions. One parent described, *I focus on the social-emotional together. His emotions can be a little out of control. He gets upset easily, and it affects him socially (P03)*. Together, the group expressed how social skills, behavior, and emotional regulation has a negative impact on other areas of their child's performance.

Theme 4: Limited Services. Ten participants (91%) described an insufficient number of therapists across professions. Specifically, examples were provided pointing to a limited number of therapists and difficulty obtaining support for behavioral issues of concern. One participant described, *even if you have a prescription for 40 hours of ABA, you'd be lucky to get 6 (P10)*. Since outpatient therapies are limited, families look to the school system as a primary resource for services. However, school services are also reportedly challenging to access as well. One participant explains, *now there're so many kids diagnosed, that the majority of kids in private*

school are getting group therapy for both speech and occupational [therapy]. And if they get one-on-one that is like 'woo-hoo party' (P10). Another participant describes additional challenges accessing school-based services stating, *my son, when he was 3 to 5 years old, maybe first grade at a public school, did not qualify for speech therapy, but he could not speak (P10).*

Theme 5: The Burden of Finding Alternative Services. Eight (73%) of the parents in the focus group mentioned having to drive long distances, spending extra money on fuel, tolls and out of pocket costs for services to address their child's needs. For some in the Lower Keys this requires a two to three-hour drive to the "mainland" to obtain necessary services. One participant described, *I drove to Miami for therapy for 5-6 days a week, because I could not find anyone [locally] (P10).* Another participant shared; *I was driving to the mainland all the time (P08).*

Theme 6: "They can't afford to live here". The cost of living in Monroe county was reported by seven of the 11 participants (64%) as the main reason for the high turnover rate for therapists in Monroe county. This problem was mentioned and revisited several times throughout the focus group discussion. Parents provided examples of high rental rates (e.g., \$1800 for 1-bedroom rental and 3-bedroom condos or home rentals ranging from \$2800-3500 per month). When discussing the high cost of living for therapists in the school system one participant stated, *they'll find people, then they'll figure out they can't afford to live here (P05).*

Theme 7: Specialized Care. Seven (64%) participants also reported concerns that health professionals and others who currently practice in Monroe county may not have the specific expertise to provide comprehensive care for children with ASD. Three sub-themes emerged within the broader issue of specialized care. Some reported feeling dismissed by providers regarding their concerns for their child. During the discussion, they reported other areas with

need for improvement as increasing levels of compassionate care, concern for the patient and effective communication.

Theme 7.1: ASD Specific Knowledge. The primary concern reported by participants was inadequate knowledge regarding the specific needs of children with ASD. Participants explained difficulty finding local health care providers equipped with the specific knowledge of ASD to provide comprehensive care for their children. A participant shared, *there are autism specialists, but we can't get to them. Well there's one in Ft. Lauderdale and there's one in Melbourne...It's critical to their recovery but it's not something that we have any actual resources to (P09).*

Theme 7.2: Empathy and Compassion. Participants also reported a desire for more empathy and compassion from healthcare providers and greater concern for their child's well-being. One participant explains, *it'd be nice if they listened to what we think. I went to a nutritionist because I couldn't find anyone that valued my thoughts of my child's healthcare and what I thought was best for him. They're very cookie cutter. And they don't have time, you know. They're in a hurry. There's two pediatricians on this entire island (P10).*

Theme 7.3: Communication. Participants also reported concerns with communication and cohesion between healthcare professionals, as well as, with the family. One participant stated, *it would be great if everybody worked together. I have a very hard time getting my whole team to work together and to keep me in the loop and with communication. Because my son gets a lot of his services through the school and they're just so busy with everything else. They are spread so thin; it's so hard to get them to write a little note once a week. They're just...everybody is spread so thin (P03).*

Discussion

The purpose of this study was two-fold: (1) to estimate the therapy needs for children within Monroe County and (2) to gain a better understanding of parent perceptions regarding services. Based on our estimates, there are potentially 210 children living with ASD in Monroe County. Although there are currently 15 board certified behavior analysts (BCBA/BCBA-D/BCaBA), 22 licensed occupational therapists (OTRs) and 20 speech language pathologists (SLPs), this is not enough to meet the estimated needs. Furthermore, only a portion of these therapists are likely to practice in pediatrics, meaning the gap may actually be larger than these estimates suggest. Thus, this study serves as a red flag and the conservative estimates presented here should be used as a starting point for further study. If the estimates here are accurate, an ideal level of care would require an additional 96 registered behavior technicians (RBTs), 27 BCBA/BCBA-Ds (according to the BACB tiered service model), 54 OTs and 25 SLPs. Of the services that are available, there are disproportionately more services available in the Lower Keys compared to the Middle and Upper Keys. Further evaluation of the uneven distribution of services across the Keys is also warranted.

Parent reports confirmed the service gap suspected and further illustrate the negative impact of limited access to services in Monroe county through their personal accounts. Parents identified concerns for their children including social skills, behavioral issues and emotional regulation difficulties; all areas that are within the scope of ABA, OT and SLP practice. Limited access to care means, not only are these concerns going unaddressed, but it may also mean increased family/caregiver stress (Boyd, 2002) and financial strain (Saunders et al., 2015) as well as increase societal costs (Järbrink & Knapp, 2001). In the current study, parents also shared personal accounts of time- and financial-related burdens when seeking alternatives to local care. For example, if the nearest multidisciplinary specialty pediatric facility is located on the

mainland in Miami-Dade County, this can require approximately 50 – 150 miles travel one-way. If therapy services are recommended for multiple professions (ABA, OT, SLP, etc.) at a frequency of one to three times per week accessing services could require extensive travel time and expenses. Collectively, parents point to the cost of living as the primary reason for reportedly high turnover rates for providers. According to a recent systematic review, family finances are also one of the most consistently identified barriers preventing families from accessing allied health therapies such as OT, SLP, ABA (Dallman, Artis, Watson & Wright, 2020). It is reasonable to suspect that the cost of living is a barrier here considering that the median home value in Monroe county (\$429,000) is two times the national value (\$217,600) (Martin, 2020), whereas the median household income in Monroe county (\$63,030) remains on par with the national median value (\$61,937) (United States Census Bureau, 2019).

In addition to concerns regarding ASD symptoms, children with ASD can also have complex medical needs that can be challenging for parents to navigate on their own (Brewer, 2018). Such medical complexities require a medical home where care from specialties and professions can be managed and monitored by one primary health care provider. When children with ASD have a medical home, they have fewer unmet needs (Farmer et al., 2014). It is clear from parent reports that there is also a need for more comprehensive medical homes for children with ASD in the Florida Keys.

Limitations

As there are no public records detailing exactly how many children are diagnosed with ASD within Monroe county, this needs assessment is based on population data and prevalence estimates. Similarly, the numbers of therapists for each profession are also based on estimates since it is unclear exactly how many of the existing therapists practice in pediatrics or work with

children with ASD. Furthermore, since there is no information available regarding the actual distribution of children with ASD, there is no way to identify whether the distribution of therapists across the islands is sufficient. Future studies could identify exactly how many children have ASD and where in the islands they are located to better understand the needs of families across all regions. Lastly, the focus group participants identified as female parents/caregivers, thus, the opinions of other genders are not reflected here. The small sample of parents included in the qualitative study and preliminary needs assessment estimates based on limited records and databases currently available prevent generalization beyond the current sample and geographical context.

Implications and Future Work

Ideally, considerable efforts should be made to reduce the impact of the high cost of living in Monroe County in an effort to recruit and retain skilled allied health care professionals. However, the issues surrounding cost of living are complex and solutions may not be feasible for addressing immediate needs. Thus, it is imperative to develop sustainable solutions that can be implemented and do not depend on modifying the cost of living.

Professionals in rural communities are often required to practice as generalists and address a wide range of needs (O'Toole et al., 2010); however, serving individuals with ASD requires specialized knowledge and expertise (Heidgerken et al., 2005). Parents in this study also expressed negative feelings regarding the lack of specialized, comprehensive care for children with ASD in Monroe county. One possible solution worth exploring is to establish collaborations with academic institutions on the mainland. To increase providers, graduate students, faculty, and staff who live and primarily work on the mainland could rotate through the local clinic on a weekly basis. In this scenario, local providers would have greater access to networking with

outside providers from various disciplines, creating a multidisciplinary environment with access to specialty care. Additional training and education for local healthcare providers regarding evidence-based practice for children with ASD and their families may also provide a viable solution. To increase access to specialized training, an education delivery model called the Extension for Community Health Outcomes (ECHO) Project (Arora et al., 2007) is gaining momentum in rural areas internationally and may be a good fit for rural island communities such as the Florida Keys. The ECHO Project's hub and spokes model utilizes telementoring to connect academic specialists (hubs) with local providers (spokes) to share knowledge and ultimately increase the capacity of local providers to deliver specialized care in rural areas (University of New Mexico, 2020). Future research regarding solutions such as these should also include stakeholders and explore expectations of both caregivers and providers regarding service provision and specialized training needs to help guide continuing education efforts.

Additionally, modified service models could be integrated into the collaborative solutions presented above where elements of traditional, continuous therapy schedules are provided primarily by local providers and episodic care schedules (Newman et al., 2016), when appropriate, are provided by rotating or remote faculty/staff/students. Blending local and long-distance providers would allow local therapists to provide a medical home and manage care coordination for patients who are medically complex. This combination would foster continuity of care locally while also providing access to specialized care remotely. A blended model such as this could increase access to services locally and reduce the burden on parents to travel in search of specialists on the mainland. Furthermore, this model would not require providers to buy/rent homes in Monroe county.

Similarly, telehealth or teletherapy is gaining momentum for its usefulness and effectiveness (Kairy et al., 2009) and has been previously recommended as a viable solution for addressing services gaps for those with ASD in rural areas (Antezana et al., 2017). This option could be incorporated into the blended practice model described above. Telehealth could include an in-person evaluation followed by flexible treatment options incorporating periods of telehealth and in-person treatment as needed. Local providers should consider integrating telehealth into their practices, when appropriate, to expand their client base and potentially partner with specialists located elsewhere. This collaboration would provide more local services, reducing the need for traveling long distances, and prevent the unfortunate alternative for some families to simply go without.

Although effective communication between healthcare practitioners and families is known to directly impact patient outcomes and clinician satisfaction (Johnson & Abraham, 2012), it is not uncommon for parents of children with ASD to report issues in communication or a lack of specialized knowledge from practitioners when learning of their child's ASD diagnosis (Rhoades et al., 2007). Similarly, parents and caregivers in Monroe county expressed concerns regarding communication issues between families as healthcare providers, as well as between providers in the area. Although coalitions exist for pre-and post-natal concerns and early child development in Monroe county, it may be beneficial to develop an organized network or coalition of allied health professionals in the area. An organized network of providers with common interests in autism and other developmental disorders could work in collaboration to improve access to services, improve communication among providers and continuity of care, as well as access to educational resources for parents and other professionals.

Conclusions

The needs assessment results, although based on estimates, clearly illustrate a large gap in ABA, OT and SLP pediatric therapy services in the Florida Keys (i.e., Monroe county). Social skills, challenging behaviors and emotional regulation are parents' greatest concerns for their children with ASD, which are all areas that can be addressed by ABA, OT and SLP services. The participants in this study are highly motivated to access and utilize OT, SLP and ABA services; however, the shortage of therapists and reported lack of specialized ASD care presents a significant barrier to families receiving the care that they need. It is reasonable to suspect that the service gaps highlighted here are at least somewhat representative of other pediatric disorders in this community. Inadequate access to care is problematic and may have a negative impact on ASD symptom severity which may be further exacerbated by any financial burdens such as the high cost of living in Monroe county and extra travel required to access services (Lin & Yu, 2015; Kerns et al., 2017). Given the unique geography, culture, and economy of the Florida Keys, it is necessary to involve local providers, policy makers, and families in the process of developing sustainable solutions. Some solutions to consider include: (a) a blended care model that integrates local, remote/telehealth and academic clinical services to fill gaps in care while circumventing the cost of living in the Keys, (b) improving communication across local professionals through organized networks and (c) providing opportunities for local providers and families to obtain specialized ASD training as indicated through collaborations with local stakeholders.

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Table 1*Focus Group Semi-Structured Interview Questions*

I.	What are your top three areas of concern for your child with autism regarding functional skills? Such as: academic performance, social skills, motor performance, behavior management, etc.
II.	What is your current knowledge of therapy services and their benefits? Such as: physical therapy, occupational therapy, speech therapy and behavioral therapy.
III.	What treatments or therapy services have you tried?
IV.	What are the most important features of a health care provider to you regarding the care provided to your child and family? This can include, convenience, cost effectiveness, client-centeredness, competence, compassion, etc.
V.	Are you familiar with team-based therapy or interdisciplinary approaches? If so, what types of professionals have you were a part of the team?
VI.	What has your overall experience with current healthcare services been like since your child was diagnosed with ASD?

Table 2

Frequency and location of certified or licensed and registered therapists active in Monroe

County, Fl as of 2020 in unspecified settings and populations.

Certification or License Type	Frequency	Frequency by Location
BCBA/BCBA-D	13	Key West (8) Little Torch Key (1) Marathon (1) Tavernier (1) Key Largo (2)
BCaBA	2	Key West (2)
RBT	9	Key West (5) Summerland Key (1) Big Pine Key (1) Key Largo (2)
OTR	22	Key West (10) Sugarloaf Key (1) Summerland Key (1) Duck Key (1) Marathon (1) Tavernier (5) Key Largo (3)
COTA	6	Key West (3) Tavernier (1) Key Largo (2)
SLP	20	Key West (10) Marathon (1) Sugarloaf Key (2) Summerland Key (1) Islamorada (1) Tavernier (2) Key Largo (3)
SLPA	1	Key West (1)

Note. BCBA/BCBA-Ds, Board Certified Behavior Analyst

BCaBA, Board Certified Assistant Behavior Analyst

RBT, Registered Behavioral Technician

OTR, Occupational Therapist

COTA, Certified Occupational Therapist Assistant
SLP, Speech- Language Pathologist
SLPA, Speech-Language Pathologist Assistant

Table 3*Summary of Needs Assessment Results for BCBA, OT and SLP Services*

	Expected time per child	Total expected time (210 children) x (10 hrs/wk)	Actual time for ASD per provider	Providers available	Total actual time (actual time) x (providers available)	Time Gap (total expected time) – (total actual time)	Provider Gap (time gap) / (actual time per provider)
Profession	(hrs/wk)	(hrs/wk)	(hrs/wk)	(number of providers)	(hrs/wk)	(hrs/wk)	(number of providers)
Board Certified Behavior Analyst (BCBA/ BCBA-Ds/ BCaBA)	10 hrs/wk	2,100	10	15	150	1,950	195
Occupational Therapists (OTRs)	2 hrs/wk	420	7	6	42	378	54
Speech and Language Pathologists (SLPs)	1 hr/wk	210	6.4	8	51	159	25

Table 4*Suggestions for Optimizing Applied Behavior Analysis Services Based on the Tiered Service**Provision Model to Address the Current Service Gap*

Role in Tiered Service Model	Total time for direct care	Portion of total time available for ASD only per provider	Supervisor hours required	Number of providers expected to achieve 2,100hrs/wk	Number of providers available from BACB registry	Number of providers needed to fill service gap
	Based on tiered service model	Based on conservative estimate that 50% of caseload has ASD	Based on (20%) supervision required per RBT	Providers Required to Meet the Needs	Providers Available	(expected – available)
RBTs (direct care)	40 hrs/wk (100%)	20 hrs/wk	4hrs/wk	105 (time needed)/ (time available per provider)	9	96
BCBAs/B CAB-Ds or BCaBAs (direct supervision of RBTs)	20 hrs/wk (50%)	10 hrs/wk	2.5 RBTs/wk	42 (number of RBTs)/ (supervisor hrs required each)	15	27

Note.

RBT, Registered Behavior Technician

ABA, Applied Behavior Analysis

BCBA/BCBA-Ds, Board Certified Behavior Analyst

BCaBA, Board Certified Assistant Behavior Analyst