

UC San Diego

UC San Diego Previously Published Works

Title

Pediatric Primary Care Perspectives on Integrated Mental Health Care for Autism

Permalink

<https://escholarship.org/uc/item/69r2t2ct>

Journal

Academic Pediatrics, 20(8)

ISSN

1876-2859

Authors

Stadnick, Nicole A
Martinez, Kassandra
Aarons, Gregory A
et al.

Publication Date

2020-11-01

DOI

10.1016/j.acap.2020.03.006

Peer reviewed

Pediatric Primary Care Perspectives on Integrated Mental Health Care for Autism

Nicole A. Stadnick, PhD, MPH; Kassandra Martinez, BA; Gregory A. Aarons, PhD; David A. Lee, BS; Jeanne Van Cleave, MD; Lauren Brookman-Frazee, PhD

From the Department of Psychiatry, University of California (NA Stadnick, GA Aarons, DA Lee, and L Brookman-Frazee), San Diego, La Jolla, Calif; University of California San Diego Dissemination and Implementation Science Center (NA Stadnick, GA Aarons, and L Brookman-Frazee), La Jolla, Calif; Child and Adolescent Services Research Center (NA Stadnick, K Martinez, GA Aarons, DA Lee, and L Brookman-Frazee), San Diego, Calif; San Diego State University/University of California, San Diego Joint Doctoral Program in Clinical Psychology (K Martinez), San Diego, Calif; General Pediatrics, Children's Hospital Colorado and University of Colorado Anschutz Medical Campus (J Van Cleave), Aurora, Colo; and Rady Children's Hospital-San Diego, Autism Discovery Institute (L Brookman-Frazee), San Diego, Calif

The authors have no conflicts of interest to disclose.

Address correspondence to Nicole A. Stadnick, PhD, MPH, Department of Psychiatry, University of California, 9500 Gilman Drive, MC 8022, La Jolla, CA 92093 (e-mail: nstadnic@health.ucsd.edu).

Received for publication October 7, 2019; accepted March 15, 2020.

ABSTRACT

OBJECTIVE: Timely identification of mental health needs and linkage to services is critical to provide comprehensive care for children with autism spectrum disorder (ASD). Pediatric primary care is well-positioned to facilitate this process through integrated care approaches. As a first step toward mental health integration, this study applied the Exploration, Preparation, Implementation, and Sustainment framework to characterize determinants of implementing integrated care practices for ASD.

METHODS: Sixty pediatric primary care providers and leaders from 3 organizations completed focus groups and surveys about identification of mental health needs in children with ASD and access to mental health services. Findings were integrated to examine convergence (ie, do the 2 methods confirm or find similar results) and expansion (ie, do the 2 methods provide insights beyond either method alone).

RESULTS: Results converged regarding 3 primary influences to integrated care practices for ASD: 1) limited specialized mental health referral options for ASD, 2) unique structural

characteristics of the mental health system act as barriers to accessing care, and 3) caregivers differ in the degree to which they understand co-occurring mental health conditions and pursue recommended services. Qualitative results provided expansion by highlighting unique implementation considerations (eg, alignment with health care delivery priorities and values) based on primary care characteristics.

CONCLUSIONS: Findings confirm need for a tailored approach for linking children with ASD to appropriate mental health treatment. Results yield insight into the needs for organizational capacity to support integrated care and provide direction toward adapting an integrated mental health care model for children with ASD.

KEYWORDS: autism; implementation science; integrated care; mental health; pediatrics; primary care

ACADEMIC PEDIATRICS 2020;XXX:1–8

WHAT'S NEW

This study reports mixed-methods perspectives from pediatric primary care to inform selection and tailoring of implementation strategies to promote adoption of integrated mental health for children with autism. Findings offer potential to reduce autism-related disparities in mental health care access.

INDIVIDUALS WITH AUTISM spectrum disorder (ASD) experience high rates of co-occurring medical and psychiatric conditions^{1–10} that necessitate care from multiple systems, which is costly and insufficiently coordinated.^{11,12} Over the past decade, there have been advancements in building capacity of children's mental health systems to care for children with ASD, and indicate that training mental health providers to adapt services for

ASD results in improved outcomes.¹³ Early and efficient identification of co-occurring mental health conditions and subsequent linkage to care is crucial to facilitate targeted and evidence-based mental health treatment. Pediatric primary care is a principal point of routine care and, with that recognition, a growing number of clinical guidelines have been developed to address medical comorbidities for children with ASD.^{14,15} Integrated care—defined here as primary care providers and mental health specialists collaborating with the family to identify mental health concerns and facilitate access to specialty mental health services¹⁶—is a promising solution to promote timely linkage to mental health care for children with ASD.

However, there are several challenges to implementing integrated care for ASD. One challenge is diagnostic overshadowing that occurs when a diagnosis like ASD conceals or precludes identification of other co-occurring

conditions.^{17–22} This phenomenon might be impacted by policies and guidelines from the American Academy of Pediatrics (AAP) regarding early screening for ASD²³ and the identification and management of adolescent depression²⁴ but not for universal mental health screening. Additionally, the structure of primary care work flows inhibit the opportunity to adequately address mental health concerns, with the average duration of pediatric primary care visits lasting only 11 to 20 minutes or less.²⁵ Further, there is a widespread scarcity of mental health providers, particularly those qualified to treat children with ASD *plus* co-occurring mental health symptoms (ASD+).

To date, there have been a small number of studies to guide thinking about best practices for integrated care for children with complex needs. In a recent study,²⁶ physicians rated their knowledge of ASD diagnosis and treatment as high but reported strong discomfort in providing care for these patients and endorsed the belief that diagnosing and treating ASD was outside of their scope of practice. Similarly, Van Cleave and colleagues (2018),²⁷ reported qualitative findings from medical specialists, primary care providers and staff, and parents of children with ASD that demonstrated support for primary pediatric care as the appropriate place for management of ASD-associated conditions. However, participants reported that primary care practices lacked ASD-specific policies and practices to facilitate co-management or care integration. Furthermore, when caring for patients with ASD, providers are faced with: 1) complexity beyond their usual role, 2) limited knowledge and resources, 3) lack of training/prior experience, 4) barriers related to communication and collaboration, 5) need for information and training, and 6) need for care coordination and systemic changes.²⁸

For this study, we used the Exploration, Preparation, Implementation, and Sustainment (EPIS) framework,^{29,30} to guide comprehensive assessment of contextual factors and implementation processes influential in integrated care implementation. The EPIS framework defines outer context (eg, AAP policies, funding for health care), inner context (eg, organizational capacity for integrated care), bridging factors (ie, those that span the outer and inner contexts), and innovation factors (ie, characteristics of the intervention, program, practice) as well as processes that may prevent or enable the implementation and sustainment of new practices (ie, determinants³¹) in health care settings.

To advance integrated care implementation for ASD+, this study had 3 objectives: 1) characterize current efforts in primary care to identify mental health needs and referral to specialty care, 2) understand the implementation factors that determine mental health need identification and care access for children with ASD, and 3) cull recommendations to directly inform specific adaptations to an integrated care model for children with ASD. In this paper, we address a special challenge: how primary care settings coordinate comprehensive screening and successful mental health linkage (ie, encompasses referral and access to mental health services) for children with ASD. Particular attention is paid to the extent to which organizational structure and the context of primary care settings

impact screening and linkage practices for children with ASD.

PATIENTS AND METHODS

This study used a concurrent exploratory quantitative + qualitative mixed-methods design³² to gather in-depth information from primary care providers and leaders to ultimately identify strategies aimed at coordinating primary and mental health care for children with ASD+.

STUDY CONTEXT

During the fall of 2017 and the spring of 2018, the study PI (N.A.S.) visited regularly scheduled staff meetings at 3 primary care health care organizations to provide an overview of the study and recruit interested providers and pediatric primary care leaders (eg, Chief of Pediatrics). The 3 organizations were: Organization 1: a linked health system with the largest pediatric primary care group in 2 Southern California counties, serving families with private insurance and Medicaid; Organization 2: a private, for profit integrated health care system that has a variety of payment systems including self-pay, employer-based private insurance and subsidized programs; Organization 3: a federally qualified health center that serves an ethnically and linguistically diverse and lower income patient population along the US/Mexico border. None of the organizations have mental health providers embedded or co-located within the pediatric primary care offices. Attendees were asked to complete a form to indicate their interest in participating in an online survey and/or a focus group. Of those who attended these meetings and completed an interest form (n = 90), 86% (n = 77) of these individuals expressed interest in participating in one or both study activities. Study procedures were approved by the University of California San Diego and participating organizations.

SURVEY PARTICIPANTS AND PROCEDURES

Survey respondents included 60 primary care providers practicing in 1 of the 3 participating health care organizations. See [Table 1](#) for sociodemographic and professional characteristics. The survey was emailed to interested providers. Participants completed the survey in an average of 15 minutes. Each participant received a \$20 electronic gift card.

SURVEY

Selected items were drawn from the Geisinger Health System's Primary Care Physician needs assessment survey³³ regarding current use of mental health screening and comfort level identifying mental health problems in children with ASD. The survey used for this study is available upon request.

FOCUS GROUP PARTICIPANTS AND PROCEDURES

A total of 42 providers and 7 pediatric primary care leaders participated in 1 of 8 focus groups and 1 key

Table 1. Participant Characteristics

	Focus Group (n = 49)	Survey (n = 60)
Age (M; SD; Range)	–	43; 11; 27–75
Gender n (%)		
Male	14 (29)	17 (29)
Female	35 (71)	42 (71)
Race/ethnicity n (%)		
White/Caucasian	29 (64)	34 (58)
Asian American/Pacific Islander	7 (16)	15 (25)
Black/African American	1 (2)	0 (0.0)
Mixed/other	8 (18)	10 (17)
Hispanic/Latinx n (%)		
Yes	8 (17)	12 (20)
Primary organization n (%)		
FQHC	10 (20)	17 (28)
Integrated health care system	10 (20)	20 (33)
Primary care medical group	23 (38)	
Provider role n (%)		
Physician	52 (87)	
Nurse practitioner or physician assistant	(13)	7 (12)
Other	(4)	1 (2)

M indicates rounded mean; SD, standard deviation; and FQHC, federally qualified health center.

For the survey, there was 1 missing data point for each of the following: Gender, Hispanic/Latinx, Race, and Primary Department; There were 2 missing data points for age.

informant interview. Providers who indicated interest in participating in a 1-hour focus group were contacted via e-mail to coordinate a convenient date. There was at least 1 provider and 1 leader focus group conducted with participants from each organization. At the time of the scheduled focus group meeting, providers who were present at the meeting location (a clinic site) and interested in joining the focus group were invited to join. There were 10 providers who did not complete an initial interest form but participated in a focus group. The average length of each focus group was 45 minutes. Each participant received a \$40 gift card. The focus group guide was constructed to support a semistructured funnel approach wherein each section started with a broad question (eg, “How do providers in your clinic make a mental health referral?”) and progressively narrowed to focus on patients with ASD (eg, “What types of modifications are made to this process for children with ASD?”).

DATA ANALYSIS

Data from the survey and focus groups were first analyzed separately. Descriptive statistics examined closed-ended items from the survey. The 2 open-ended survey items were coded by 2 members of the research team (D. L. and N.A.S.) and then analyzed descriptively.

Next, data from the focus groups and interview were transcribed. To start, 2 focus groups (1 representing each participant group, Providers and Leaders) were selected and examined independently by the 2 coders to identify a priori and emergent codes. The 2 coders and the PI (N.A.S.) met to discuss the summarized notes from these codes

and develop a codebook that corresponded with outer and inner context factors outlined in the Exploration and Preparation phases of the EPIS framework.^{29,30} An additional 2 focus groups were selected and independently coded to ensure adequate coverage and depth of the codebook. Segments of text, ranging from sentences to paragraphs, were assigned specific codes, considering the frequency of and salience with which a topic was discussed to enable members of the research team to consolidate interview data into analyzable units. Following this, the 2 team members and the PI met to identify and reconcile discrepancies in code assignment and finalize the codes. After consensus was achieved during the open coding, all transcripts were then entered, coded, and analyzed in NVivo.³⁴ Co-occurring codes were identified and discussed with the research team. Content analysis using a constant comparison methodology was used to finalize a priori and emergent themes.^{35,36}

Following the independent analysis of data, the quantitative and qualitative data were integrated to examine convergence (ie, do the 2 methods confirm or find similar results) and expansion (ie, do the 2 methods provide insights beyond either method alone).^{32,37}

RESULTS

CURRENT EFFORTS IN PRIMARY CARE TO IDENTIFY MENTAL HEALTH NEEDS AND ACCESS SPECIALTY MENTAL HEALTH CARE FOR CHILDREN WITH ASD+

Respondents were asked to report how many of their patients with ASD had additional mental health problems (eg, anxiety, attention deficit hyperactivity disorder, and depression). The majority of respondents (78%) reported that at least 10% of their patients with ASD exhibited co-occurring mental health conditions. The majority also endorsed using a mental health screening instrument to identify non-ASD mental health symptoms (72%); the most common were the Patient Health Questionnaire (PHQ) 2 or 9, the Vanderbilt Assessment Scale, the Generalized Anxiety Disorder Screener-7, the Pediatric Symptom Checklist and the Screen for Child Anxiety Related Disorders. About half of the respondents (52%) reported administering one of the screening instruments annually and half of the respondents (48%) endorsed using the results of the mental health screen “most of the time or always” to inform their referral decision. Regarding referral practices for patients with ASD, 50% of respondents reported that they refer at least 25% of their pediatric patients with ASD to a mental health provider. Of those who they refer, 52% were “unsure” if the child attended a mental health appointment. Additional quantitative results are provided in [Table 2](#).

IMPLEMENTATION DETERMINANTS OF IDENTIFYING MENTAL HEALTH NEEDS AND ACCESSING SPECIALTY CARE

The focus group data largely converged with the quantitative survey data. Three themes represented as implementation challenges were present across all health care

Table 2. Primary Care Infrastructure for Mental Health Screening and Referral for Children With ASD

Characteristics of patients with ASD in primary care			
Percentage of patient panel with known ASD diagnosis	<10%	47 (78%)	
	10%–25%	11 (18%)	
	Unsure	2 (3%)	
Proportion of pediatric patients with ASD and co-occurring mental health needs (ASD+)	<10%	9 (15%)	
	10%–25%	17 (28%)	
	>25%	30 (50%)	
Most frequent co-occurring mental health conditions in patient panel with ASD	Unsure	4 (7%)	
	ADHD	55 (92%)	
	Disruptive behaviors	50 (83%)	
	Anxiety	41 (68%)	
	Depression	16 (27%)	
Eating disorders		13 (22%)	
	Mental health screening in primary care for patients with ASD		
	Most frequently used mental health screening instrument for patients with ASD	PHQ-2/9	42 (70%)
		NICHQ Vanderbilt Assessment Scale	11 (18%)
		GAD-7	10 (17%)
Pediatric symptom checklist		5 (8%)	
SCARED		5 (8%)	
Frequency of mental health screening administration for patients with ASD	Rarely	11 (18%)	
	At least once per year	31 (52%)	
	At most visits	1 (2%)	
	Not applicable	17 (28%)	
Primary care provider use of mental health screening results to refer patients with ASD to mental health care	Never	2 (33%)	
	Sometimes/half time	12 (20%)	
	Mostly/always	29 (48%)	
	Not applicable	17 (28%)	
Primary care provider use of the EHR to administer and/or score mental health screening instrument	Yes	16 (27%)	
	No	44 (73%)	
Mental health referral for patients with ASD			
Percentage of pediatric patients with ASD referred to a mental health provider through primary care	<10%	11 (18%)	
	10%–25%	13 (22%)	
	>25%	30 (50%)	
	Unsure	6 (10%)	
Percentage of pediatric patients with ASD referred through primary care who scheduled and completed a mental health appointment	<10%	3 (5%)	
	10%–25%	7 (12%)	
	>25%	19 (32%)	
	Unsure	31 (52%)	
Primary care provider use of EHR to refer pediatric patients with ASD to mental health providers	Yes	46 (77%)	
	No	14 (23%)	

ASD indicates autism spectrum disorder; ADHD, attention deficit hyperactivity disorder; PHQ-2/9, Patient Health Questionnaire 2 or 9; NICHQ, National Institute for Children's Health Quality Vanderbilt Assessment; GAD-7, Generalized Anxiety Disorder Screener-7; SCARED, Screen for Child Anxiety Related Disorders; and EHR, Electronic Health Record.

organizations. Each challenge aligns with one of the EPIS domains. The results of this objective are summarized in a joint display in [Table 4](#) and discussed in the following section. In addition, we highlight unique implementation determinants based on the organizational structure of the health care systems.

Theme 1: Limited specialized mental health referral options for ASD+ (EPIS Framework Outer Context). Providers reported limited knowledge about the most efficient referral pathways and effective mental health referral sources for their pediatric patients, and especially for their patients with ASD. Primary care provider (PCPs) reported that they have difficulty identifying symptoms beyond ASD that require specialized attention from mental health providers (eg, challenging behaviors, anxiety) as opposed to services targeting ASD-specific needs (eg, speech therapy, applied behavior analysis). PCPs expressed concerns about the significant lack of qualified mental health providers who have the appropriate training and program capacity to treat children with ASD+ in a timely fashion.

These issues are further exacerbated by the convoluted and, often, disconnected funding landscape for children with ASD to access mental health and other services. For example, children with ASD may be eligible to receive behavioral services through private insurance mandates, special education services through the public education system, and mental health care through Medicaid. Because of this clinical and funding complexity, PCPs described that they spend a significant amount of uncompensated time assisting families of children with ASD to access mental health services.

Theme 2: Unique structural characteristics of the mental health system act as barriers to coordination, communication and access to care (EPIS Framework Bridging and Innovation Factors). One example is the inability for medical providers to view their patients' treatment notes written by their mental health provider, even when all providers are working in the same health care system and using the same electronic health record. PCPs described how this, and similar communication barriers contribute

to difficulties in continuity of care and act as disincentives for PCPs to refer and follow up about mental health referrals. In addition, PCPs expressed frustration that psychiatry is primarily accessed through “self-referral” meaning that the patient is responsible for initiating contact with the specialty health care provider rather than the PCP being able to directly schedule or connect the patient to the specialist.

Theme 3: Primary care providers perceive variable caregiver readiness to pursue recommended mental health services as a challenge to service access (EPIS Framework Inner Context). Providers observed that the extent to which parents pursue recommended care services may be influenced by how caregivers perceive the need for and prioritize their child’s mental health care vis-à-vis their child’s other health needs and services. Additionally, PCPs noted that because caregivers of children with ASD are generally overwhelmed, accessing mental health care through self-referral is insufficient to effectively link families to the appropriate mental health services. PCPs highlighted the need for dedicated case management or navigation to help these families successfully access and engage with mental health care.

While all 3 organizations emphasized similar determinants to appropriate mental health linkage for children with ASD, qualitative differences among the 3 organizations were identified. Organization 1 emphasized using multiple strategies, including technological, organizational, and stakeholder-involved strategies, to facilitate cross-system communication. Organization 2 reported on the need to improve the efficiency of service delivery for all children, but especially for children with ASD. Organization 3 highlighted the importance of considering values integral to the medical home model, including patient-

centered care and explicit care coordination to ensure consistency of services.

RECOMMENDATIONS TO ADDRESS IMPLEMENTATION DETERMINANTS AND INFORM SPECIFIC ADAPTATIONS TO AN INTEGRATED CARE MODEL FOR CHILDREN WITH ASD+

Qualitative data revealed that dedicated personnel or strategies for mental health care coordination and technology-based solutions would enhance mental health needs identification and access to care for patients with ASD. For example, changes to the electronic health record to streamline referral channels and workflows could serve as a technology-based solution. The quantitative findings provided more specific strategies that could be targets for adapting integrated care practices for ASD+. Specifically, PCPs were asked to rate the extent to which each implementation strategy would be most helpful for mental health screening and mental health referral for children with ASD. The top-rated strategies were associated with three primary functions: enhanced mental health needs identification and monitoring, streamlined referral pathways to specialty mental health care for ASD+ and efficient communication between primary and mental health care providers (see Table 3 for specific strategies).

DISCUSSION

This mixed-methods study reports perspectives of PCPs and leaders regarding 1) current efforts to identify mental health needs and facilitate access to specialty care and 2) implementation determinants (ie factors that prevent or enable implementation) defined by the EPIS framework²⁹ to integrated mental health services for children with ASD+. The synthesis of these perspectives provides

Table 3. Recommendations to Improve Mental Health Screening and Access to Care for ASD+

	% Slight Extent	% Moderate Extent	% Great Extent	% Not Applicable
Mental health screening recommendations				
% agreed with each recommendation				
The EHR is a good place to screen for MH problems	44.06	25.42	27.12	3.39
Care would be improved if a MH screening instrument were administered at every patient visit	32.20	35.59	32.20	0.00
I would use MH screening instruments if no/minimal scoring is required by me	18.64	20.34	55.93	5.08
I would use MH screening instruments if they are computer-administered in the waiting room	18.64	11.86	67.80	1.69
I would use MH screening instruments if patient responses were tracked over time	10.17	15.25	75.54	0.00
I would use MH screening instruments if responses were automatically scored and sent to me	11.86	11.86	76.27	0.00
Mental health referral recommendations				
I need more help to decide when to refer to MH	28.81	37.29	33.90	0.00
The EHR is a good place to make a referral to MH	23.73	20.34	49.15	6.78
I would refer to MH if I received confirmation through the EHR when a MH appointment has been scheduled	25.42	16.95	55.93	1.69
Mental health access recommendations				
Patients with ASD require more help to access MH	25.42	23.73	49.15	1.69
Care would be improved if I regularly communicated with the MH providers to whom I refer	18.64	20.34	61.01	0.00
Care would be improved if a care coordinator/navigator assisted families with MH referrals	3.39	5.08	89.84	1.69

EHR indicates Electronic Health Record; MH, Mental Health; and ASD, autism spectrum disorder. Each item was asked in reference to “patients with ASD.”

Table 4. Joint Display of Convergent Mixed-Methods Results: Implementation Determinants Organized by EPIS Domain

EPIS Domain	Qualitative Themes and Illustrative Quotes	Quantitative Findings
Outer context	<p>Theme 1: Limited specialized mental health referral options for ASD+.</p> <p>+<u>Limited knowledge about the most efficient and effective mental health referral sources.</u> "... we don't know to whom we're supposed to refer... or how soon [the child is] going to be able to get in." [Org. 3]</p> <p>+<u>Mental health referral further complicated by the clinical needs and complexity of children with ASD.</u> "... [children with ASD] often have certain needs... it's hard to say like, is that [issue] something I would deal with, or somebody else would deal with..." [Org. 1]</p> <p>+<u>Lack of specialized training in ASD and co-occurring mental health conditions.</u> "... it's really hard to know if their behaviors are part of their [ASD]... or if it is a mental health issue." [Org. 2]</p> <p>◇<u>Significant amount of uncompensated time spent trying to help families access MH services.</u> "[In pediatrics], people just... ask us to do more and more... but there's no [one] say[ing], 'Okay, well we are going to give you... more time...'" [Org. 3]</p>	<p>Comfort with mental health screening and referral practices (1 = not at all – 10 = very)</p> <p>Identifying non-ASD mental health problems M = 5; SD = 2</p> <p>Interpreting non-ASD mental health screening results M = 6; SD = 2</p> <p>Awareness of mental health resources M = 5; SD = 2</p> <p>Care coordination M = 5; SD = 2</p>
Bridging and innovation factors	<p>Theme 2: Unique structural characteristic of the mental health system act as barriers to coordination, communication and access to care.</p> <p>+<u>Lack of communication between PCPs and mental health providers.</u> "It feels like a little bit of a disconnect because it's psychological services... it's this whole other area that people have to go to, and it's not necessarily something that we're involved with." [Org. 1]</p> <p>◇<u>Mental health is primarily accessed through "self-referral."</u> "... [Self-referral from primary care to specialty mental health care] doesn't work that way for any other specialty. I don't know if anybody calls somebody to get more numbers to call somebody to call somebody to get more numbers." [Org. 1]</p>	<p>The top-rated challenges were:</p> <ol style="list-style-type: none"> 1) limited access to mental health care (26%) 2) lack of closed-loop communication with the mental health system (21%), 3) difficulty identifying ASD and co-occurring mental health needs (13%), 4) concerns that mental health screeners are not suitable for patients with ASD (13%)
Inner context	<p>Theme 3: Caregivers differ in the degree to which they understand co-occurring mental health conditions and pursue recommended mental health services.</p> <p>◇<u>Variability in parents' perception of the need for mental health care.</u> [Caregivers often say] "No, but [my child is] already getting services... Like, another visit, another thing, like, I'll deal with that later." [Org. 3]</p> <p>◇<u>Caregivers of children with ASD± are generally overwhelmed; self-referral is insufficient.</u> "They're already overwhelmed with the fact that their child is completely, oftentimes, unmanageable. And then we give them this list of seven phone numbers... they're just wanting to throw their hands up after they've tried for a few times." [Org. 1]</p>	

M indicates rounded mean; SD, standard deviation; ASD, autism spectrum disorder; and PCPs, Primary Care Provider.
 + represents convergence of QUAN data and QUAL themes.
 ◇ represents expansion of findings provided by the QUAL or QUAN data.

specific direction on adaptations needed for a tailored integrated care model (ie, comprehensive screening and successful mental health linkage) for children with ASD+ to accelerate access to needed mental health care.

Findings that addressed the first study objective indicated that children with ASD+ represent the majority of patients with an ASD diagnosis seen in primary care. However, the primary mental health screening instrument administered, the PHQ-2/9, was not designed to detect the most common PCP-reported co-occurring mental health conditions observed in children with ASD: attention deficit hyperactivity disorder, disruptive behaviors, and

anxiety. The choice of the PHQ-2/9 aligns with the outer context policy recommendations from the AAP to screen for adolescent depression²⁴ but it may reinforce the diagnostic overshadowing phenomenon known to occur for individuals with ASD.^{17–22} In addition, more than 50% of PCPs reported that they were unsure whether their referred patients with ASD are subsequently connected to mental health services (ie, whether they attended a mental health appointment vs simply being referred).

The second study objective sought to better understand the challenges of these current integrated care efforts for children with ASD. Results indicated that implementation

determinants of integrated mental health care for ASD span the outer and inner contexts of the health care ecosystem and align with the key themes identified broadly in the patient-provider health care literature.²⁸ First, in addition to the general shortage of child and adolescent mental health providers, there is a distinct shortage of specialized providers to care for patients with ASD+. Second, PCPs emphasized that mental health is a unique health care specialty not only because of the content addressed but because of the systemic and organizational structures that act as barriers to access and engagement with mental health providers. Third, caregivers were perceived as instrumental in both facilitating and impeding, albeit unintentionally, the mental health linkage process. A vast literature has raised awareness about the high levels of stress and strain on resources (time, financial, and social) that are experienced by caregivers of individuals with ASD.^{38,39} Findings from the current study confirm this and highlight that a self-referral to mental health care is insufficient as well as the need for dedicated service navigation for families to successfully access mental health services.

Because these data were collected from multiple health care systems, we were additionally interested in understanding the extent to which organizational context impacted perceptions. Results suggested that a key driver of differences related to the funding structure and associated values-based care models of each health care system. For example, there was a values focus on enhancing efficiencies for the private, for profit system versus a values focus on adherence to the medical home model within the federally qualified health center. Finally, results highlighted several recommendations for targeted adaptations to integrated care for ASD+. First, PCPs highlighted the helpfulness of leveraging technology solutions to address some of the identified mental health needs identification, coordination, and communication challenges. Second, selection of a mental health screening instrument needs to consider both fit within the current workflows and policies of primary care settings and ability to detect the most common co-occurring mental health conditions observed in children with ASD. Third, dedicated mental health navigation for families of children with ASD may be particularly important to support and accelerate access to appropriate mental health services. Because resources are scarce, it could be important to prioritize resource allocation of navigation to children with complex needs like ASD.

Several strengths and limitations are noteworthy. One of the primary strengths and limitations of this study is the singular focus on primary care patients with ASD. Children with ASD and developmental disabilities have complex, multifaceted clinical presentations and resulting care needs. Although a longer term goal is generalization of this learning to the broader pediatric population, we opted to start with a well-specified pediatric group as a proof-of-concept for adaptation and tailoring. Another strength of this study is the inclusion of multiple types of health care organizations (ie, a network of pediatric primary care

clinics, a private, for profit system and a federally qualified health center). Including these diverse organizations offered the opportunity to learn how screening and linkage practices currently operate and which pieces are feasible to be uniformly modified across organizations and which pieces require customization to fit the workflows, resources and infrastructure of each specific organization. The primary limitations are methodological in nature. Specifically, not all respondents who completed the survey also participated in a focus group due to variable interest and availability. In addition, we focused the sample on pediatric primary care providers and leaders, who were predominantly MDs. It is acknowledged that there are other important clinical and administrative staff who are involved in providing or supporting pediatric care (eg, nurses, medical assistants, information technology analysts). It was beyond the scope of this study to include all of these stakeholders. However, the next step in this research is to synthesize these data to inform specific adaptations to an integrated care model that will be customized based on organizational characteristics and engagement with a broader range of clinical, administrative, and technology stakeholders.

ACKNOWLEDGMENTS

We would like to acknowledge the qualitative data analytic support from Dr Angela Petersen. We would also like to acknowledge the feedback and discussion provided by members of the ATTAIn Advisory Group who reviewed preliminary results from the data reported in this manuscript. Finally, we would like to acknowledge the evaluative feedback and editorial comments from Dr Timothy Sahms who reviewed a draft of this manuscript.

Financial statement: This work was supported by a National Institute of Mental Health grant (K23MH110602; PI: Stadnick). Additionally, Drs Stadnick and Brookman-Frazee were fellows and Dr Aarons is core faculty with the Implementation Research Institute (IRI), at the George Warren Brown School of Social Work, Washington University in St Louis; through an award from the National Institute of Mental Health (R25MH080916).

REFERENCES

1. Brookman-Frazee L, Stadnick N, Chlebowski C, et al. Characterizing psychiatric comorbidity in children with autism spectrum disorder receiving publicly funded mental health services. *Autism*. 2018;22:938–952.
2. Stadnick N, Chlebowski C, Baker-Ericzén M, et al. Psychiatric comorbidity in autism spectrum disorder: correspondence between mental health clinician report and structured parent interview. *Autism*. 2017;21:841–851.
3. Joshi G, Petty C, Wozniak J, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: a large comparative study of a psychiatrically referred population. *J Autism Dev Disord*. 2010;40:1361–1370.
4. Bresnahan M, Hornig M, Schultz AF, et al. Association of maternal report of infant and toddler gastrointestinal symptoms with autism: evidence from a prospective birth cohort. *JAMA Psychiatry*. 2015;72:466–474.
5. Buie T, Campbell DB, Fuchs GJ, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. *Pediatrics*. 2010;125(Suppl 1):S1–S8.
6. Ibrahim SH, Voigt RG, Katusic SK, et al. Incidence of gastrointestinal symptoms in children: a population-based study. *Pediatrics*. 2009;124:680.

7. Singh K, Zimmerman AW. Sleep in autism spectrum disorder and attention deficit hyperactivity disorder. *Semin Pediatr Neurol*. 2015;22:113–125.
8. Goldman SE, Richdale AL, Clemons T, et al. Parental sleep concerns in autism spectrum disorders: variations from childhood to adolescence. *J Autism Dev Disord*. 2012;42:531–538.
9. Hill AP, Zuckerman KE, Hagen AD, et al. Aggressive behavior problems in children with autism spectrum disorders: prevalence and correlates in a large clinical sample. *Res Autism Spectr Disord*. 2014;8:1121–1133.
10. Sikora DM, Vora P, Coury DL, et al. Attention-deficit/hyperactivity disorder symptoms, adaptive functioning, and quality of life in children with autism spectrum disorder. *Pediatrics*. 2012;130(Suppl 2):S91–S97.
11. Lavelle TA, Weinstein MC, Newhouse JP, et al. Economic burden of childhood autism spectrum disorders. *Pediatrics*. 2014;133:e520–e529.
12. Wang L, Leslie DL. Health care expenditures for children with autism spectrum disorders in Medicaid. *J Am Acad Child Adolesc Psychiatry*. 2010;49:1165–1171.
13. Brookman-Frazee L, Roesch S, Chlebowski C, et al. Effectiveness of training therapists to deliver an individualized mental health intervention for children with ASD in publicly funded mental health services: a cluster randomized clinical trial. *JAMA Psychiatry*. 2019;76:574–583.
14. Malow BA, Byars K, Johnson K, et al. A practice pathway for the identification, evaluation, and management of insomnia in children and adolescents with autism spectrum disorders. *Pediatrics*. 2012;130(Suppl 2):S106–S124.
15. Furuta GT, Williams K, Kooros K, et al. Management of constipation in children and adolescents with autism spectrum disorders. *Pediatrics*. 2012;130(Suppl 2):S98–S105.
16. Peek CJ. *Lexicon for Behavioral Health and Primary Care Integration: Concepts and Definitions Developed by Expert Consensus*. Rockville, Md: Agency for Healthcare Research and Quality; 2013. Available at: <http://integrationacademy.ahrq.gov/sites/default/files/Lexicon.pdf>. Accessed April 23, 2020.
17. Jopp DA, Keys CB. Diagnostic overshadowing reviewed and reconsidered. *Am J Ment Retard*. 2001;106:416–433.
18. Mason J, Scior K. ‘Diagnostic overshadowing’ amongst clinicians working with people with intellectual disabilities in the UK. *J Appl Res Intellect Disabil*. 2004;17:85–90.
19. Meera SS, Kaipa R, Thomas J, et al. Brief report: an unusual manifestation of diagnostic overshadowing of pervasive developmental disorder—not otherwise specified: a five year longitudinal case study. *J Autism Dev Disord*. 2013;43:1491–1494.
20. Reilly C, Senior J, Murtagh L. ASD, ADHD, mental health conditions and psychopharmacology in neurogenetic syndromes: parent survey. *J Intellect Disabil*. 2015;59:307–318.
21. Reiss S, Levitan GW, Szyszko J. Emotional disturbance and mental retardation: diagnostic overshadowing. *Am J Ment Defic*. 1982;86:567–574.
22. Rush KS, Bowman LG, Eidman SL, et al. Assessing psychopathology in individuals with developmental disabilities. *Behav Modif*. 2004;28:621–637.
23. Zwaigenbaum L, Bauman ML, Fein D, et al. Early screening of autism spectrum disorder: recommendations for practice and research. *Pediatrics*. 2015;136(Suppl 1):S41–S59.
24. Zuckerbrot RA, Cheung A, Jensen PS, et al. Guidelines for adolescent depression in primary care (GLAD-PC): part I. Practice preparation, identification, assessment, and initial management. *Pediatrics*. 2018;141:e20174081.
25. Halfon N, Stevens GD, Larson K, et al. Duration of a well-child visit: association with content, family-centeredness, and satisfaction. *Pediatrics*. 2011;128:657.
26. Ghaderi G, Watson SL. “In medical school, you get far more training on medical stuff than developmental stuff”: perspectives on ASD from Ontario physicians. *J Autism Dev Disord*. 2019;49:683–691.
27. Van Cleave J, Holifield C, Neumeyer AM, et al. Expanding the capacity of primary care to treat co-morbidities in children with autism spectrum disorder. *J Autism Dev Disord*. 2018;48:4222–4230.
28. Morris R, Greenblatt A, Saini M. Healthcare providers’ experiences with autism: a scoping review. *J Autism Dev Disord*. 2019;13:1–5.
29. Aarons GA, Hurlburt M, Horwitz SM. Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Admin Policy Ment Health Ment Health Serv Res*. 2011;38:4–23.
30. Moullin JC, Dickson KS, Stadnick NA, et al. Systematic review of the Exploration, Preparation, Implementation, Sustainment (EPIS) framework. *Implement Sci*. 2019;14:1.
31. Flottorp SA, Oxman AD, Krause J, et al. A checklist for identifying determinants of practice: a systematic review and synthesis of frameworks and taxonomies of factors that prevent or enable improvements in healthcare professional practice. *Implement Sci*. 2013;8:35.
32. Palinkas LA, Aarons GA, Horwitz S, et al. Mixed method designs in implementation research. *Admin Policy Ment Health Ment Health Serv Res*. 2011;38:44–53.
33. Meadows T, Hosterman S, Parikh M. Pediatric primary care behavioral health: from innovation to application. *Workshop Conducted at the Annual Conference of the Society for Pediatric Psychology*. San Diego, Calif; 2015.
34. Bazeley P, Jackson K, eds. *Qualitative Data Analysis With NVivo*. London, England: Sage Publications Limited; 2013.
35. Palinkas LA, Mendon SJ, Hamilton AB. Innovations in mixed methods evaluations. *Annu Rev Public Health*. 2019;40:423–442.
36. Hamilton AB. *Qualitative Methods in Rapid Turn-Around Health Services Research*. U.S. Department of Veteran Affairs; December 11, 2013. Available at: https://www.hsrd.research.va.gov/for_researchers/cyber_seminars/archives/video_archive.cfm?SessionID=780. Accessed April 23, 2020.
37. Aarons GA, Fettes DL, Sommerfeld DH, et al. Mixed methods for implementation research: application to evidence-based practice implementation and staff turnover in community-based organizations providing child welfare services. *Child Maltreat*. 2012;17:67–79.
38. Pastor-Cerezuela G, Fernández-Andrés MI, Tárrega-Mínguez R, et al. Parental stress and ASD: relationship with autism symptom severity, IQ, and resilience. *Focus Autism Other Dev Disabil*. 2016;31:300–311.
39. Valicenti-McDermott M, Lawson K, Hottinger K, et al. Parental stress in families of children with autism and other developmental disabilities. *J Child Neurol*. 2015;30:1728–1735.