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Pediatric Primary Care Perspectives on Integrated Mental Health Care for Autism

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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

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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

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 services \$^{16}— 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 over shadowing 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 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, determinants 31) 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 colocated 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 MASKED, MASKED, and MASKED.

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 informant interview. Providers who indicated interest in participating in a 1-hour focus group were contacted via email 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 close 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, ADHD, 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 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. 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-a-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 path ways 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 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: ADHD, 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 eco system and align with the key themes identified broadly in the patient-provider health care literature. 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. 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.

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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.

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.

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.

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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%)
	Unsure	4 (7%)
Most frequent co-occurring mental health conditions in patient panel with ASD	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		

10%-2	0/01/	(0/01) 11
	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%-2	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		46 (77%)
No		14(23%)

ASD indicates autism spectrum disorder; ADHD, PHQ-2/9, Patient Health Questionnaire 2 or 9; NICHQ, GAD-7, Generalized Anxiety Disorder Screener-7; SCARED, Screen for Child Anxiety Related Disorders; and EHR, Electronic Health Record.

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Table 3.

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

	% Slight Extent	% Moderate Extent % Great Extent % Not Applicable	% Great Extent	% Not Applicable
Mental health screening recommendations		% agreed with each recommendation	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."

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Table 4.

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

EPIS Domain	Qualitative Themes and Illustrative Quotes	Quantitative Findings	sāt
Outer	Theme 1: Limited specialized mental health referral options for ASD+. ±Limited knowledge about the most efficient and effective mental health referral sources. "we don't know to whom we're supposed to referor how soon [the child is] going to be able to get in." [Org. 3] ±Mental health referral further complicated by the clinical needs and complexity of children with ASD. "[children with ASD] often have certain needsit's hard to say like, is that [issue] something I would deal with, or somebody else would deal with [Org. 1] ±Lack of specialized training in ASD and co-occurring mental health conditions. "it's really hard to know if their behaviors are part of their [ASD]or if it is a mental health issue [Org. 2] Significant amount of uncompensated time spent trying to help families access MH services.	Comfort with mental health screening and referral practices (1 = not at all - 10 = very) Identifying non-ASD M = 5; SD mental health problems Interpreting non-ASD M = 6; SD mental health	In health I practices = very) M = 5; SD = 2 M = 6; SD = 2
	[in penatrics], people Just ask us to do more and morebut there's no lone] say[ing], Okay, wen we are going to give youmore time" [Org. 3]	screening results Awareness of mental M health resources Care coordination M	M = 5; $SD = 2M = 5$; $SD = 2$
Bridging and innovation factors	Theme 2: Unique structural characteristic of the mental health system act as barriers to coordination, communication and access to care. ±Lackof communication between PCPs and mental health providers. "It feels like a little bit of a disconnect because it's psychological servicesit's this whole other area that people have to go to, and it's not necessarily something that we're involved with." [Org. 1] Mental health is primarily accessed through "self-referral." "[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." [Org. 1]	The top-rated challenges were: 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	e: unication n (21%), and co- ls (13%), h screeners vith ASD
Inner context	Theme 3: Caregivers differ in the degree to which they understand co-occurring mental health conditions and pursue recommended mental health services. Variability in parents' perception of the need for mental health care. [Caregivers often say] "No, but [my child is] already getting servicesLike, another visit, another thing, like, I'll deal with that later." [Org. 3] Caregivers of children with ASD± are generally overwhelmed; self-referral is insufficient. "They' re already overwhelmed with the fact that their child is completely, oftentimes, unmanageable. And then we give them this list of seven phone numbersthey' re just wanting to throw their hands up after they' ve tried for a few times." [Org. 1]	(%(51)	

M indicates rounded mean; SD, standard deviation; and ASD, autism spectrum disorder.

represents expansion of findings provided by the QUAL or QUAN data.