

CHILDREN'S MENTAL HEALTH CARE NEEDS ASSESSMENT IN SIX RURAL  
NORTHERN CALIFORNIA COUNTIES

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## **Abstract**

### **CHILDREN'S MENTAL HEALTH CARE NEEDS ASSESSMENT IN SIX RURAL NORTHERN CALIFORNIA COUNTIES**

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Mental health problems affect millions of children and adolescents each year. Furthermore, the prevalence of these difficulties may be higher among children living in rural communities. Primary care providers are playing a larger role in the treatment of mental health challenges in youth. The present study examined the experiences and knowledge of rural parents and primary care providers regarding children's mental health care.

While providers practicing in six counties were invited, all respondents ( $N = 19$ ) practiced in Humboldt County. Parents were recruited through schools which agreed to distribute the survey. Ten principals in four counties agreed, including Del Norte, Humboldt, Siskiyou, and Trinity counties. Responding parents ( $N = 65$ ) resided mostly in Humboldt and Del Norte counties.

Most parents in need of services for their child were unaware of where to go to initiate treatment. While many parents reported their child's primary care provider as the first professional to whom they raised concerns. Primary care providers reported rarely administering socioemotional assessments. Additionally, most primary care providers

indicated that they lacked access to mental health care specialists to whom they could refer youth.

The present findings suggest that tangible barriers appear most salient for both parents and providers in rural areas. Thus, recommendations were made regarding addressing gaps in care, including, but not limited to, increasing providers' knowledge of trauma-informed care and the co-location of a mental health specialist within primary care. Parents of children struggling with mental health problems often experience stress and concern about their child's functioning. Rural parents often turn to their child's primary care provider as an authority on how to best help their child. However, providers often lack specialized training and the time needed to conduct thorough assessments.

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## **Introduction**

The National Institute of Mental Health (NIMH) indicates that in any given year, one in five children is diagnosed with a mental health disorder (NIMH, 2016). The Center for American Progress reported that 13.7 million children in the United States are affected by mental health problems each year (Russel, 2010). Additionally, a report published by Robinson and colleagues through the Centers for Disease Control and Prevention (CDC) indicates higher prevalence rates of mental, behavioral, and developmental disorders among children living in rural areas (<50,000 residents), compared to urban areas (Robinson et al., 2017).

In recent years, however, it has become clear that these diagnoses are often not made by qualified mental health professionals. A study examining national trends in both child (0-13 years) and adolescent (14-20 years) outpatient mental health care showed that there was a significant increase in the rate of non-psychiatric physicians diagnosing mental health disorders. This was especially true for disruptive behavior disorders and mood disorders (Olfson, Blanco, Wang, Laje, & Correll, 2014).

Moreover, the recent changes to psychiatric nosology of the DSM-5 (APA, 2013) have some critics concerned that over-diagnosis will become commonplace (Batstra, Hadders-Algra, Nieweg, Van Tol, Pijl, & Frances, 2012; Frances, 2012; Hyman, 2010; Wakefield, 2013). Specifically, decontextualization when assessing mental health problems, the DSM's diagnostic categories having questionable validity, and financial conflicts of interest may all contribute to over-diagnosis of mental health disorders in

children. These flaws are important to recognize as many physicians rely on the DSM when diagnosing children or providing treatment recommendations.

Since primary care physicians are becoming the most common source of mental health diagnosis and care, their role in the delivery of mental health services must be examined. Pediatricians' involvement in the assessment and treatment of behavioral and emotional difficulties in children has increased over time (Olfson et al., 2014). Thus, there is an increased need to understand the processes involved and perspectives of these primary care providers. The current study investigated how providers view various child mental and behavioral health problems, how comfortable and knowledgeable they are regarding assessment and treatment, how aware they are of local mental health resources, and their prescription practices. In light of the increased use of psychotropic medicine to treat child and adolescent mental health symptoms (Howie, Pastor, & Lukacs, 2014), parents' knowledge and beliefs about mental health treatment and the efficacy and dangers of such drugs was also assessed in the current study.

Children do not seek treatment on their own, so parents are the most important resource for children seeking mental health care services. Thus, gaining insight into parents' experiences of perceived barriers to obtaining services for their children is critical. Polaha, Williams, Helflinger, and Studts (2015) found that parents were less likely to seek services at a mental health center when they reported greater levels of perceived stigma regarding mental health challenges. Dempster, Wildman, and Keating (2013) investigated perceived public stigma against both parents and children and found that stigma was negatively related to help seeking behavior. The current study expands on

these findings by examining both intangible barriers, such as stigma, and tangible barriers, such as not being able to miss work, in a rural population where these barriers may be greater.

Statistics gathered in 2013 show that in all six counties included in this study, primary care resources are strained. The person to primary care physician ratio ranges from 3,360:1 in Trinity County to 1,050:1 in Mendocino County (County Health Rankings & Roadmaps, 2016). While these numbers do not include other primary care providers, such as physicians' assistants and family nurse practitioners, the strain placed on physicians in rural, underserved counties has a spillover effect onto other medical specialists, who may have little training in treating children's mental health problems. Thus, the current study also examined the knowledge and practice of physicians' assistants and nurse practitioners regarding childhood mental health. To this end, the goal of the current study was to better understand both providers' and parents' perceptions and experiences regarding children's mental health care in six rural counties.

## Review of Literature

Child and adolescent service utilization for mental and behavioral health problems presents a unique set of circumstances that are difficult to explain with adult health models. Research on service utilization has traditionally focused primarily on adult physical health care service utilization. Models such as the sociobehavioral model (SBM; Andersen, 1995) and the health belief model (HBM; Rosenstock, Strecher, & Becker, 1988) are popular in research on service utilization. These models will be briefly explained and the reasons for their limited usefulness in assessing mental health care service utilization will be examined. Next, a model designed specifically for investigating mental health care will be introduced. After reviewing the adult model and explaining why it does not accurately capture the experience of mental health care utilization by youth, a child model stemming from this framework will be discussed. Finally, a description of the Gateway Provider Model will be given, detailing why this model is most appropriate for assessing youth access to mental health care.

The sociobehavioral model (SBM) examines an individual's need for health care services, both actual and perceived, "predisposing characteristics" for a health problem, such as age and socioeconomic status, and "enabling characteristics," including local resources and health insurance coverage. Health insurance benefits and the organizational structure of health care are key components of "enabling characteristics" within this model (Andersen, 1995). This model also takes into consideration how an individual's experience within the health care system may change their need, predisposing, and

enabling characteristics over time (Andersen, 1995). The major emphasis of this model is on the health care system and the “enabling characteristics” of the individual, such as insurance coverage, which hinder or promote access to health care services.

The second framework, the health belief model (HBM), is more concerned with individual belief characteristics, including the health beliefs an individual holds, than with organizational factors (Rosenstock et al., 1988). Within this model, an individual’s beliefs about personal susceptibility to illness, illness severity, treatment, and preferences regarding care, determine service utilization. Action to seek health care services is the end result of an individual examining and weighing perceived benefits of care against perceived barriers to care, conceptualized within this framework as both tangible barriers and psychological costs (Rosenstock et al., 1988).

A major critique of these models is the failure to capture the processes by which individuals access mental health care. These models operate under the assumption that the decision to seek care is a rational choice made out of individual and systemic static characteristics. An additional limitation of these models, in explaining mental health care service utilization, is the assumption that service utilization transpires in a linear fashion whereby an individual seeks treatment from a single source and receives treatment from that same source. In practice, individuals seeking mental health care services often attempt to access services from multiple sources before actually receiving specialty mental health treatment (Shanley, Reid, & Evans, 2008). Therefore, it is necessary to examine a framework that has been specifically designed to capture the nature of mental health care service utilization, which does not require such assumptions.

Pescosolido and Boyer (1999, 2010) developed a model of mental health care service utilization that considered the dynamic social contexts of help-seeking, addressing not only who receives care, but the details of how mental health problems unfold. The Network-Episode Model (NEM) recognizes that the assumption of rational choice is not always met when one is in need of mental health care services. An individual is sometimes required to take part in mental health treatment through the legal system; this access to care is not the product of the individual's rational decision-making process, but a matter of coercion. The NEM recognizes that the initiation of mental health treatment is often a dynamic process that involves multiple factors including, but not limited to, the individual's demographic characteristics, the community resources for mental health, and the attitudes and beliefs regarding mental health treatment held by members of the individual's social network (Pescosolido & Boyer, 1999, 2010). A key difference between the NEM and both the SBM and the HBM is that the NEM recognizes that those experiencing mental health problems often lack the ability to participate in the complex cognitive tasks on which the other two frameworks rely. For example, an individual struggling with major depression may have difficulty in maintaining the persistence which is often required to access mental health services, due to the deficits stemming from depression. In addition, the NEM places an emphasis on the individual's social context, which is lacking in the HBM, and it focuses more on the treatment networks within the SBM.

The differences between these models highlight varied perspectives regarding the means through which individuals take action to access health care services. The purpose

of all three is similar, to examine the factors associated with utilization, with the intention being to use the information to increase levels of utilization. However, the utility of the NEM for this purpose far surpasses that of the earlier frameworks discussed due to the inclusion of a dynamic social component, which influences individual experiences of mental health problems. Also, it recognizes that accessing specialty mental health care services often involves multiple nonlinear steps, as opposed to a single event or rational choice. This will be discussed in more detail next.

### **Network-Episode Model (NEM)**

The foundational premise of the NEM is that individuals' decisions while dealing with mental health problems originate within a dynamic social process (Pescosolido & Boyer, 1999, 2010). An individual has a variety of social contacts within their community and the treatment system. The treatment system within this model is conceptualized as a fluctuating set of treatment organizations and providers from which an individual receives treatment. These contacts, or social networks, contribute to the decision to seek treatment, with influence equal to that of personal action. Interactions between the individual and their social network regarding mental health symptoms drive the process of service utilization. Service use is not conceptualized as a single, one-time decision, but an ongoing process, influenced by the individual's day-to-day experiences with symptoms and the responses evoked from others in their environmental context (Pescosolido & Boyer, 1999, 2010).

The utility of this model is best demonstrated through an example of an individual experiencing a form of psychological distress, such as anxiety symptoms. The individual recognizes that they are distressed and that the symptoms are impacting their functioning. With these factors held stable, the SBM would predict that with need established, through impaired functioning, the individual's health insurance coverage would be a key factor in determining whether or not services are utilized. In contrast, the HBM would focus on what benefit the individual perceives might come from treatment as well as a consideration of the potential barriers to and costs of treatment. While recognizing that these factors may influence service utilization, the NEM also examines the attitudes and beliefs held by the individual's immediate social context including, but not limited to, close friends, intimate partner, and/or work colleagues, regarding treatment. The attitudes held by the larger community network are important factors the NEM considers. If the individual experiencing anxiety has a social network that is resistant to mental health care, it is unlikely that the individual will seek out specialty mental health care services, even though there is established need.

The NEM takes into account important individual characteristics, such as social and geographical location, personal health background, and characteristics of the problem. These factors shape an individual's social context and influence both the social network and the treatment system. All these systems contribute to the pattern of action an individual takes when experiencing a mental health problem (Pescosolido & Boyer, 1999, 2010).

To better understand the various pathways to care, one must recognize the power and content of the “community,” defined in the NEM as the social systems to which the individual is connected. Communities will vary in their influence on a person’s coping and help-seeking behaviors, depending on size, experiences with the mental health system, and attitudes regarding mental health care (Pescosolido & Boyer, 1999, 2010).

The NEM captures the dynamic processes involved in adult mental health service utilization; however, this model must be revised when examining the pathways to care and service utilization for youth experiencing mental or behavioral health problems.

### **Children’s Network-Episode Model (CNEM)**

The major distinction between adult service use and that of children and adolescents is that youth do not usually seek out services without adult initiation. This shift in power in decision making presents a unique factor that must be addressed in any model of youth mental health care service utilization.

Recognizing this, Costello, Pescosolido, Angold, and Burns (1998) revised the NEM to better reflect the process involved in accessing treatment for youth mental and behavioral health problems. The major reconceptualization is a shift from focusing on community influence to family influence. The family network is considered the primary support system made available to the child and their influence is key throughout the model (Costello et al., 1998). Other subcomponents in this model include the school network and community network. The social context is influenced by predisposing

characteristics of both the child and family and in turn influences both the family network and the community of treatment systems (Costello et al., 1998).

Another important reconceptualization in this framework is the influence that a parent's recognition of the child's problem has on the youth's coping behavior. Before any steps towards services can be attempted, parents must recognize the child's functioning level and perceive their thoughts, feelings, or behaviors as problematic (Costello et al., 1998).

The community influences, detailed in the NEM, are indirectly affecting youth experiencing a mental health problem in the CNEM. The influences from the community level filter down to shape the family network's attitudes, perceptions, and beliefs regarding accessing professional mental health treatment (Costello et al., 1998). There are often many pathways to general care which parents consult prior to seeking specialized mental health care for their children. These pathways often consist of individuals within the parent's support system, such as friends, community religious leaders, or social service workers. The pathway to service delivery and the type of service provided may be very different for a child who has private health insurance and a child who is not covered. If a family network holds negative beliefs and attitudes about mental health treatment, the child's pathway to service may be different than if more positive views are held.

The CNEM model helps illuminate the dynamic processes involved when a child manifests problem thoughts, feelings, or behaviors. Service utilization by children and adolescents is a complex process, with multidimensional factors operating in various systems. Children, with less autonomy over their own treatment, are subjected to

additional influences that do not impact adults experiencing mental health challenges. However, despite the contributions of this framework, the CNEM fails to adequately explain the specific pathways to receiving mental health care that children may experience. The Gateway Provider Model aims to clarify the specific path children take to receiving care.

### **The Gateway Provider Model**

As stated above, it is important to recognize that most children's pathway to mental health treatment begins with the recognition of the problem by an adult. These persons are considered "gateway" providers and their knowledge, perceptions, resources, and recognition are often critical to youth receiving services.

In addition to parents, Stiffman et al. (2000) detail the four service sectors that may also act as gateway providers: the juvenile justice system, the child welfare system, the education system, and primary health care systems. In examining these four sectors and the role they play in adolescents receiving services, Stiffman et al. (2000) found that gateway providers' recognition and assessment of the problem and knowledge of resources explained significant variance in referral to services over and above what was explained by the youth's self-report of symptom severity and impairment.

A more complete picture of youth mental health care considers characteristics of the child and family, as well as the influence of the gateway providers who initiate the pathway to care. The Gateway Provider Model (Stiffman, Pescosolido & Cabassa, 2004) is an elaboration of the CNEM, which considers the dynamic influences of the child's

social context, social systems, and treatment systems. The model adds a consideration of gateway providers' perceptions and knowledge, as well as the organizational structure and climate of the providers' practice.

The systemic organization through which a provider is employed often has an established hierarchy of authority and division of labor, as well as normative beliefs and practice standards (Glisson, 2002). Together, these factors influence the gateway providers' decisions regarding mental health services for youth. Depending on the provider's practice resources, knowledge regarding mental health, perceptions of local mental health resources, and levels of burden, treatment recommendations will fluctuate (Stiffman et al., 2004). Level of burden is conceptualized within this framework as a physician's caseload. The current study, assessing factors that contribute to youth access (or lack thereof), to mental and behavioral health care services, is largely based upon this model, specifically examining primary health care providers as gateway providers.

The Gateway Provider Model examines the characteristics of the child and caregiver in regard to "need characteristics," "enabling characteristics," and "predisposing characteristics" (Stiffman et al., 2004). Predisposing characteristics, within this framework, consist of demographic variables, as well as risk and protective factors of both child and caretaker. If a child is presenting symptoms of depression, the severity and impairment of symptoms are examples of need characteristics. Enabling characteristics include factors such as the availability of resources within the community, the parents' ability to navigate the system, the child's health insurance coverage, and the presence (or lack thereof) of community stigma surrounding mental health care. These factors can

influence service utilization directly; however, they tend to also have indirect effects, acting through the gateway providers' perceptions and knowledge.

Organizational characteristics, such as culture, climate, and burden also influence the gateway providers' perceptions and knowledge (Stiffman et al., 2004). These factors can relate to how easily the organization can adapt to new protocol, or engage in continuing education (Glisson, 2002). The organizational climate can include factors such as a chaotic work environment, poor leadership, or high rates of burnout among colleagues. An organization's culture is what typically defines normative behaviors and can also relate to the ability to adopt new policies and procedures. In regard to mental health care specifically, the American Psychiatric Association contributes to the culture surrounding diagnosis and treatment through the diagnostic manual the organization publishes, which has important limitations.

### **Limitations of the DSM-5**

The Diagnostic and Statistical Manual of Mental Disorders 5 (APA, 2013), is the most widely used tool in the United States for the diagnosis of child mental health disorders. Its use goes beyond supplying the criteria for making diagnoses in clinical practice as it also grounds research (Whooley, 2014). However, there are several limitations in the use of the DSM-5; the most problematic, perhaps, is its lack of scientific validity. This can be demonstrated by its lack of emphasis on contextual factors, including the removal of the previous multi-axis system, in which Axis IV represented psychosocial and contextual factors contributing to an individual's symptoms

(APA, 2013). While the APA indicates that contextual factors should still be considered, it does not provide recommendations to clinicians on how to note such factors (Kress, Minton, Adamson, Paylo, & Pope, 2014). Additionally, high rates of comorbidity between disorders reduce scientific validity (Merikangas et al., 2010).

The DSM also has an unclear definition of the concept of “mental disorder.” Defining symptoms as abnormal or extreme calls for an understanding of an individual's social context (Whooley, 2014). However, the use of distinct and separate categories, where all criteria hold the same weight, along with indicating an arbitrary clinical cut-off point, does not adequately recognize the contextual factors involved in an individual's distress (Maser, Norman, Zisook, Everall, Stein, Schettler, & Judd, 2009).

The conceptualization of mental disorders as distinct disease categories operates on the assumption that psychopathology is separate from normal or subclinical conditions. This assumption is challenged by empirical research, which demonstrates that there is a continuum between typicality, subclinical symptoms, and clinical diagnoses (Maser et al., 2009). Moreover, the symptom characteristics, such as severity ratings, are more than mere biological or behavioral expressions, but are shaped not only by an individual's experiences of distress, but also how others in an individual's life experience that person's distress (Pescosolido & Boyer, 2010).

When the DSM-III (APA, 1980) established the definitions of mental disorders through symptom clusters, it was theorized to be a necessary, temporary step, until advances in neuroscience and genetics determined potential biological markers for mental disorders (Whooley, 2014). Unfortunately, there have not been clear and definitive results

from research thus far to support a categorical approach to conceptualizing psychopathology. Genetic links are more likely to relate to continuous dimensions of behaviors instead of categories developed from clinical consensus and consisting of primarily face validity (Maser et al., 2009).

Moreover, there is no definitive, objective test to indicate that an individual has a mental disorder. This makes diagnosing mental health conditions more challenging than other health conditions. Due to the lack of specific biological or brain markers to denote specific mental dysfunctions, classification through symptomology continues to be necessary. Hyman (2010) argues that it may have been scientifically premature to create many distinct, specific, and discontinuous categories. For example, a nationally representative survey found that 42% of all adolescents (13-18 years old) diagnosed with a mental health disorder meet criteria for two or more disorders (Merikangas et al., 2010). Relatively few studies have examined comorbidity rates in younger children, with no nationally representative studies conducted to date. However, Egger and Angold (2006) found that among preschool aged children (2-5 years of age), comorbidity was as common as rates found in adolescent samples. Children meeting criteria for one psychological disorder had a 49.7% chance for meeting criteria of a second disorder.

This comorbidity between disorders highlights the limited validity of discrete DSM categories. Caron and Rutter (1990) suggested that perhaps conceptualizations of separate disease categories are incorrect and that psychopathology could be better understood as existing along a continuum. Instead of a child having distinct disorders, symptoms like hyperactivity, inattention, and aggression may be risk factors for a general

category of disruptive behaviors (Caron & Rutter, 1990). Critics of the DSM also argue that there is an increased risk of pathologizing behaviors in children and young people that were previously viewed as “normal” (Batstra et al., 2012), due to the expansion and creation of new disorder categories in the DSM-5.

The DSM, as the gold standard for evaluating mental health symptoms, greatly influences the delivery of care to children suffering from emotional or behavioral health problems. This can impact the environmental contexts of gateway providers, who contribute to mental health care (or the lack thereof) for youth. These issues with the DSM can influence primary care providers’ perceptions of emotional and behavioral problems in children and can contribute to decisions gateway providers make regarding treatment trajectory.

The current study assessed the use of the DSM-5 among primary care providers. The Gateway Provider Model highlights that providers’ knowledge and perceptions about mental health care shape their treatment recommendations. The DSM provides physicians with information on mental health problems and in this way, can directly impact treatment decisions. Assessing the use of the DSM-5 and providers’ typical treatment plan for specific mental health problems illuminates the influence of the DSM-5 within a primary care setting.

### **Primary Care Providers’ Role as Gatekeepers**

As stated earlier, primary care providers are playing a larger role in diagnosing and treating children’s emotional and behavioral health problems. Anderson et al. (2015)

examined where children (2-21 years old) were receiving mental health care services, as well as trends in psychotropic medication prescriptions. The study examined children who had received care for ADHD, anxiety, or mood disorders. Results showed that 34.8% of children who had received services only saw their primary care provider and that nearly half of children had a primary care provider involved in their treatment (Anderson et al., 2015). Of the children who were seen by a primary care provider for any mental health problem, 70.2% were prescribed medication. Children who saw a psychiatrist for ADHD were one and a half times less likely to be prescribed medication, as compared to children who were seen by a primary care provider (Anderson et al., 2015). With the involvement of primary care providers in child and adolescent mental health, it is important to understand their levels of training, knowledge, and comfort in assessing, treating and managing emotional and behavioral problems.

To address these issues, Pidano, Kimmelblatt, and Neace (2011) investigated pediatric primary care providers' experience in providing mental health services. Their sample included a variety of specialties, such as family and pediatric practitioners, advanced registered nurses, and physician's assistants. Results showed that providers were significantly more comfortable with assessing, rather than treating, most disorders. For ADHD and learning disorders, providers felt equally comfortable with both assessment and treatment (Pidano et al., 2011). In the case of ADHD, approximately 79% of providers indicated that they would provide further assessment themselves. This trend was also seen for simple phobia (64.6%), generalized anxiety (62.5%), and depression

(56.3%). These disorders also had a high percentage of physicians indicating they would prescribe medication as the key treatment.

These results highlight a possible link between the use of the DSM-5 and the actions taken in primary care. Medication was the first line treatment for the disorders providers felt most comfortable treating. The DSM-5, as the gold standard used by physicians for mental health diagnosis, contributes to a medical/disease model surrounding treatment. Due to medication being a first line treatment option, primary care providers may forego a thorough assessment and write a prescription instead of a referral.

Pidano et al. (2011) found that there were often barriers to providers referring patients to mental health care services. A lack of available mental health specialists to whom to refer patients was a common complaint, with 40% of the sample indicating that patients waited 3-6 months for a mental health appointment. With such difficulties in seeing a mental health specialist, providers may feel an obligation to initiate treatment, specifically for challenges where they believe medication is a viable treatment option.

To further investigate these issues, Pidano, Honigfeld, Bar-Helpern, and Vivian (2014) compared physicians who had access to a mental health professional for consultation to those who did not. Results indicated that 44.5% of primary care providers had some form of relationship with a mental health specialist. Physicians with a relationship with a mental health provider indicated greater access to consultation regarding medication (Pidano et al., 2014). Having access to consultation regarding medication use does not indicate how often consultations are sought, or the conditions

that might require consultation. Unfortunately, this study did not address these more nuanced issues.

One study did investigate pediatricians' perspectives of four common forms of treatment for children with mental or behavioral health problems: medication, community-based care, hospital-based care, and parent training programs (Dempster and Wildman, 2015). Physicians were asked about the effectiveness and local availability of such programs. Physicians indicated that parent-training and counseling would be the most effective forms of treatment (Dempster & Wildman, 2015). Referring the patient to a specialist was preferred over providing counseling themselves, prescribing medication, or watchful waiting (withholding any form of treatment until symptoms worsen). Providers who perceived fewer available local resources were more likely to prescribe medication (Dempster & Wildman, 2015). These results suggest that often physicians recognize the benefits of referral, but due to a perceived lack of local resources, they are more inclined to prescribe medication, rather than implementing watchful waiting.

Primary care providers are limited in their knowledge and training regarding youth mental and behavioral health challenges, as well as having limited access to mental health specialists (Smith et al., 2014). This impacts their treatment recommendations, through the mechanisms detailed in the Gateway Provider Model, and often leads to the prescription of psychotropic medication. Along with training, knowledge and greater availability of local mental health resources may greatly impact treatment decisions.

This study examined physicians' preferences regarding various treatment options for several common mental health disorders. Primary care gateway providers, specifically

in rural locations, may play a larger role in access to care for youth than in the urban samples assessed in the above provider studies.

Location has been shown to affect the rates at which physicians prescribe psychotropic medication (Segool et al., 2013). For example, a sample of 516 pediatricians recruited from the American Academy of Pediatrics, was placed in one of four categories based on the population size, ranging from small nonmetropolitan (<20,000 residents), to urban (>200,000 residents). Rates of psychotropic medication prescription were then compared across groups, controlling for pediatrician training. For stimulant medications, prescription rates were similar across population groups. However, for all other classes of psychotropic medication measured, there were significantly more prescriptions in the small nonmetropolitan regions. This supports the idea that with more limited mental health care resources for children, primary care providers are more likely to supply treatment, and most likely in the form of medication.

It is important to understand where gaps in care are so that effective measures can be taken to improve treatment delivery for children. This may be more critical in rural communities, where resources are extremely limited. Few studies have specifically investigated rural primary care physicians' perspectives on children's mental health care. To this end, the current study sought to better understand how location and resource availability impact children's access to mental health care and the quality of that care. It also examined whether psychotropic medications are used more often to treat youth with emotional or behavioral problems in primary care settings, perhaps due to the lack of mental health resources associated with rural areas (Segool et al., 2013).

## **Psychotropic Medication Use in Children and Adolescents**

The National Center for Health Statistics (Howie et al., 2014) found that 7.5% of children and adolescents, aged 6-17, had taken a psychotropic medication for a behavioral or emotional difficulty within the past six months. The report detailed demographic information and showed 5.2% of girls and 9.7% of boys were on such medication. Children covered under Medicaid or Children's Health Insurance Program (CHIP) were most likely to use psychotropic medication for behavioral or emotional problems, compared with children with no insurance or private insurance (Howie et al., 2014). Trends among adolescents aged 12-19 showed that 6.3% had taken a psychotropic medication within the past month (Jonas et al., 2013); the two most common were antidepressants (3.2%) and stimulant medications used to treat ADHD (3.2%). The most relevant finding in the report is that of the adolescents taking psychotropic medication, only 43% had seen a mental health professional within the previous year (Jonas et al., 2013), suggesting that children are receiving medication from primary care providers instead.

When prescribing these medications for children and adolescents, it is recommended by the Food and Drug Administration (FDA) that the child be seen regularly to ensure correct dosage, to look for the presence of side effects, and to examine efficacy. This may be challenging to accomplish for a variety of reasons, including physician and family schedules, as well as insurance coverage, which may place limits on physician visits for mental health purposes (Rynn et al., 2011). Even when a child is

monitored to the extent recommended by the FDA, there is limited research on the effects of long-term medication use on child and adolescent brain development (Thomas, Mitchell, & Batstra, 2013).

The use of medication should be reserved for those cases that are severe and for which behavioral therapies have been unsuccessful (Rynn et al., 2011). However, this is often not the case; medication is often the first-line treatment. This may be more evident in rural populations, where primary care providers play a larger role in treatment. This practice is common across subtypes of psychotropic medications, including second-generation antipsychotics.

Second-generation antipsychotic (SGA) medications have been used increasingly with children and adolescents (Harrison, Cluxton-Keller, & Gross, 2012). The FDA approves the use of second-generation antipsychotics in children and adolescents with severe emotional/behavioral disorders; however, there has been an increase in their “off-label” use. “Off-label” refers to the use of a medication to treat a non-FDA approved condition. An example is the prescription of a SGA for the behavioral symptom of aggression that can accompany ADHD (Christian et al., 2015). There has been a two to five-fold increase in the off-label use of antipsychotic medications among children under six years old (Egger, 2010). The FDA-approved disorders for these medications in children include bipolar I disorder, schizophrenia, the behavioral symptoms of autism spectrum disorder, and Tourette’s syndrome (Pathak et al., 2010). However, with no longitudinal studies completed on SGA use in children, both on-label and off-label use may pose serious risks to youth development (Penfold et al., 2013).

While there are still many questions left unanswered, there is established evidence that SGA medications can cause an increased risk of multiple health problems, along with increased risk of suicide in children and adolescents. The risk of suicide increases further if one is concurrently taking an antidepressant medication (FDA, 2016). Unfortunately, concurrent use of SGA along with another psychotropic medication is more the rule than an exception (Kreider et al., 2014).

A study using a large nationally representative sample of children (6-11) and adolescents (12-18) found that 85% of participants who had used a SGA in the past year used another psychotropic medication concurrently (Kreider et al., 2014). Second-generation antipsychotics were used concurrently with 52% of mood stabilizers, 37% of anti-anxiety medications, 32% of antidepressants, and 22% of stimulants. Children with ADHD, which was the most common diagnosis, were the driving force behind SGA concurrent use increase, specifically those without comorbidity (40%), suggesting that these serious medications are being used more frequently outside of the scope of a severe mental disorder (Kreider et al., 2014).

Galéra et al. (2014) found that after controlling for the presence of ADHD symptoms, children were more likely to receive medication if they were male and their mother had a low education level. Moreover, most stimulant medication prescriptions came from pediatricians who are often untrained in behavioral and mental health assessment and treatment (Anderson et al., 2015).

Few longitudinal studies have followed stimulant users from childhood into adulthood, so the long-term effects on children's development are unknown (Thomas et

al., 2013). However, side effects of the most common stimulant medications, methylphenidates and amphetamines, include hepatotoxicity (chemical-driven liver damage), weight loss, and/or thoughts of suicide (Ruggiero et al., 2012).

Due to the serious side effects of medication and their unknown risks, these medications should be used only in the most severe cases and when other treatments have been ineffective (Thomas et al., 2013). Unfortunately, parents often yield to the authority of the physician, due to their own lack of knowledge regarding effective treatments for mental and behavioral problems.

Qualitative interviews by Cormier (2012) discovered that the desire to do what was best for one's child contributed to a parent's choice of initiating psychotropic medication. Preceding the decision, parents stated that their children and households were struggling. When parents attempted to seek out alternative treatments to medication, the process was challenging. This was compounded by feelings of distress within the household and pressure from school faculty to control the child's disruptive behaviors. Cormier (2012) notes that most parents went to primary care providers for alternative options to medication, with many frustrated by the lack of direction and information on how to access alternative treatments to medication.

The current study surveyed parents and providers about their knowledge and opinions regarding psychotropic medicine. Parents' perceptions of their child's symptoms, as well as their knowledge of resources, can influence their decision to seek treatment. It is a parents' concern for their child that brings the primary care provider into the system of care. Public knowledge and understanding, or lack thereof, can influence

child and parent thoughts, attitudes, and choices, which are filtered through the support network provided within the community.

### **Parents' Role in Children's Mental Health**

Few studies have examined the barriers that parents face when attempting to obtain mental health care services for their child. Brown et al. (2014) conducted interviews with low-income parents who had raised concerns to primary care pediatricians about their child's behavioral or emotional problems. Parents, recruited from an urban primary care facility, had previously received a referral to a mental health center for their child. Researchers found three main themes regarding parents' experiences in help-seeking: difficulty in knowing if problem behaviors warranted services, the information provided and procedures undertaken by their child's pediatrician were felt to be inadequate, and that parents were not provided enough information on what to expect at a mental health appointment. These results suggest that parents face multiple barriers to accessing services for their child.

Another study with a similar sample examined tangible barriers, such as "I do not have transportation to get to the appointment," and intangible barriers, such as stigma and beliefs about mental health (Larson, dosReis, Stewart, Kushner, Frosch, & Solomon, 2013). Results indicated that higher levels of intangible barriers were negatively associated with attendance at a mental health appointment; however, tangible barriers were not associated with attendance levels (Larson et al., 2013). The current study sought to understand the role of both tangible and intangible barriers to parents accessing mental

health care for their child in rural locations. Parents in rural areas may be more greatly impacted by barriers, as access to resources is limited, and there could be higher levels of stigma associated with seeking treatment.

The above studies were conducted on children who had received a referral to a mental health professional. The current study examined barriers that may be present prior to such a referral, by including three subgroups of parents: those who have received services for their child's problems, those who are seeking services but have yet to access them, and those who are not in need of services. The current study is unique in seeking to compare need, enabling, and predisposing characteristics across parents within each of these three subgroups. Parents of children experiencing a mental health problem, who have not yet accessed services for their child, will perhaps have more challenging predisposing characteristics, such as low socioeconomic status, than the other two subgroups. These parents may also lack enabling characteristics such as transportation or health insurance coverage for their child. Enabling characteristics also include intangible barriers such as the level of acceptability of mental health treatments within the community.

Dempster, Wildman, and Keating (2013) studied what impact stigma had on parent help-seeking behaviors. Stigma was measured in rural parents, examining possible stigma effects on hypothetical parenting class attendance. Results indicated that parents who had lower levels of stigma regarding having a child who requires mental health treatment, expressed greater likelihood of attending a parenting class; however, this relationship depended on children's symptom severity in that the relationship was not

significant for parents of children with more severe symptoms. Instead of investigating the impact of stigma on parents' hypothetical participation in services, this study examined whether stigma is a factor in parents initiating actual services for their children in their real lives. This is a measure more critical to understanding the relationship between children's mental health symptoms and parents' help-seeking behavior.

The need for additional research regarding rural parents of children with behavioral and emotional problems was recognized by Polaha et al. (2015), who investigated perceived public stigma, in parents living in Appalachia. Only parents of children who had borderline to severe scores on the Pediatric Symptom Checklist were asked to participate in their study. Along with assessing levels of stigma, parents were asked to indicate locations where they might attempt to access services. These locations included traditional and nontraditional sources, such as a behavioral health center, private office, two-way video conference, or a church. Results indicated that with higher levels of reported public stigma, parents were less likely to seek services across all treatment settings. However, the overall rates of perceived stigma among parents were low. This suggests that perhaps personal-stigma beliefs are more influential than perceived public stigma. It is possible that public stigma has less of an impact on parents who are seeking services for their child.

Unlike the above studies on parents of children with moderate to severe symptoms who had already received a referral, the current study included a range of parents. Parents include those with children who have previously received services, those with concerns but no previous access to services, and those with no concern and no

history of treatment. This method captures a more complete picture of rural parents' knowledge, perceptions, and experiences regarding children's mental health care services.

## The Current Study

The current study is a needs assessment project which was conducted in six rural northern California counties. No previous study has examined primary care providers' experience, knowledge, and comfort level in regard to diagnosing, treating, and referring children with mental health symptoms in rural, underserved areas, where they play a substantial role as gateway providers. Levels of burden were assessed through caseload demographics to better understand the structural influences impacting physicians' treatment decisions. Stiffman et al. (2000) found that gateway provider knowledge and connectedness with local mental health resources increase recognition of youth emotional or behavioral problems and access to treatment; all of these factors were assessed within the current study.

In this study, both barriers to service access and factors that support service utilization were examined. Moreover, no other study examining parental experiences also measures knowledge and beliefs about psychotropic medication. This study assessed this crucial variable, which may have lasting impacts on children's developmental trajectories.

Finally, no other study has examined both primary care providers' and parents' perspectives on children's mental health care in the same community. To be able to effectively address any possible gaps in care and improve treatment access, delivery, and efficacy, it is important to understand the perceptions and beliefs regarding youth mental

health problems held by parents, the child's family network, and the community network to which both child and parent are connected.

The findings of this study will be shared with local agencies, medical staff, and schools, initiating conversations regarding current practices in providing mental health care services to children. Additionally, results will be used to help address current gaps in care, as well as promote a public health framework emphasizing an interdisciplinary approach to providing mental health services to children.

Because this was an exploratory needs assessment with no clear or consistent previous research upon which to draw conclusions, no directional hypotheses were generated. However, several key research questions were identified.

Research Question 1. What are the prevalence rates, by county, of youth with emotional or behavioral problems reported by both primary care providers and parents?

Research Question 2. What are the assessment tools most often used by primary care providers for youth patients experiencing mental, emotional, or behavioral health symptoms?

Research Question 3. What is the most common treatment decision provided to youth by primary care providers?

Research Question 4. What do primary care providers indicate are the most challenging barriers in connecting youth to mental health care?

Research Question 5. How are demographic characteristics of both parents and children related to parent subgroup membership?

Research Question 6. What pathway to treatment is most used by children who have previously received services for an emotional and/or behavioral problem?

Research Question 7. What is the most challenging barrier for parents whose children need but have not received services for an emotional and/or behavioral health problem?

Research Question 8. What do parents believe is the most effective treatment for common disorders such as ADHD, depression, and anxiety?

Research Question 9. What are parents' understandings regarding the use of psychotropic medications as treatment for emotional and/or behavioral problems in youth?

## Method

### Participants

The study sample consisted of 19 primary care providers who responded to an email invitation to participate. While medical professionals in all six counties were invited to participate, all the medical professionals who participated practiced within Humboldt County. See Table 1 for primary care provider demographics.

Sixty-five parents with children between 4 – 17 years of age responded to the invitation to participate. See Table 2 for parent demographics. Additionally, parent participants were placed in subgroups defined by both their child's experience of mental, emotional, or behavioral health problems and mental or behavioral health treatment. Parents of children who had previous experience with mental health treatment are referred to as "clients" ( $N = 24$ ). Parents' of children who had or were currently experiencing a mental, emotional, or behavioral health problem, but had not received treatment are referred to as "in need" ( $N = 15$ ). Finally, subgroup three is comprised of parents of children who had not required treatment for mental, emotional, or behavioral health problems. These families are referred to as "comparisons" ( $N = 26$ ).

Analysis of variance indicated that groups did not differ in age,  $F(2, 59) = 2.62, p = .08, \eta^2 = .05$ . Additionally, parent subgroups did not differ by gender ( $p = .39, Fisher's exact test$ ), race/ethnicity ( $p = .33, Fisher's exact test$ ), or employment ( $p = .09, Fisher's exact test$ ). However, results indicated that both parent education level ( $p = .04, Fisher's$

*exact test*) and marital status ( $p = .03$ , *Fisher's exact test*) were related to subgroup membership. A greater proportion of parents within both the “in need” and “client” subgroups (75% and 73% respectively) had less than a bachelor's degree education level compared to comparison parents (36%). Likewise, a greater proportion of parents within the comparison subgroup (83%) were married compared to both “in need” (58%) and “client” parents (50%). These group differences suggest that parent predisposing characteristics may play an important role in not only children's mental health care service access but also the manifestation of symptoms.

## **Measures**

Due to the lack of previous research on this topic, a survey was created specifically for the current study. In developing the survey, the Gateway Provider Model was used to determine which provider factors might be included. These include providers' perceptions and knowledge concerning youth behavioral and emotional challenges, level of burden, and organizational factors such as the use of reliable assessment instruments and dependence on the DSM-5.

**Primary care provider survey.** The survey was adapted from the work of Pidano and colleagues (Pidano, 2007; Pidano et al., 2011; Pidano et al., 2014). The survey examined primary care providers' experiences in assessing, diagnosing, and treating nine mental health problems in youth. See Appendix A for the primary care provider survey. Specific conditions assessed include ADHD, anxiety, autism spectrum disorder,

depression, bipolar disorder, oppositional-defiant disorder, post-traumatic stress disorder, and substance abuse.

***Organizational factors.*** To assess the organizational factors that may be impacting treatment decisions, providers indicated their caseload and the demographics of their patients, the percentage insured by Medicaid or CHIP, and the percentage of the youth they serve who experience emotional, behavioral, or mental problems.

Providers were asked to indicate any training they may have received on child mental health or behavioral pediatrics. The use of the DSM-5 was measured through providers indicating what diagnostic tool they use most often for evaluating mental, emotional, or behavioral health challenges. Additionally, providers were asked if this tool was consulted prior to each diagnosis.

Providers were asked to indicate how regularly they use reliable assessment instruments for youth behavioral and emotional problems, including Beck Youth Inventories (BYI; Beck, Beck, & Jolly, 2001), the Child Behavior Checklist (CBCL; Achenbach, 1994), the Child Depression Inventory (CDI; Kovacs, 1985), the Pediatric Symptom Checklist (PSC; Jellinek, Murphy, & Burns, 1985), Parents' Evaluation of Developmental Status Questionnaire (PEDS; Glascoe, 2013), Adverse Childhood Experiences Questionnaire (ACE; Felitti et al., 1998), and the Patient Health Questionnaire-9 (PHQ-9; Korenke et al., 2001). Answers were provided on a 4-point Likert scale, with 1 representing *never* and 4 representing *nearly always*. See Appendix A for the primary care provider survey.

***Provider knowledge and perceptions.*** The provider survey assessed primary care providers' knowledge and perceptions regarding youth mental health problems. Providers were asked to indicate their comfort level in assessing, diagnosing, and treating each of the nine disorders listed above. Answers were provided on a 4-point Likert Scale, with 1 representing *not at all comfortable* and 4 representing *completely comfortable*.

Providers reported barriers to the recognition and assessment of youth behavioral and emotional problems, such as not being reimbursed, having too little knowledge and/or time, lack of access to specialists, and concern regarding stigma or labeling of children.

Providers also indicated whether they have access to a mental health specialist for consultative purposes. Related to this, providers also indicated their awareness of community mental health resources to which they may refer patients.

***Provider treatment decisions.*** Providers were asked about their treatment protocols for youth presenting emotional or behavioral problems and the likelihood of initiating psychotropic medication, referring to a psychiatrist, and referring to a psychologist or community mental health agency. Answers were provided on a 4-point Likert scale, with 1 representing *not at all likely* and 4 representing *completely likely*. See Appendix A for the primary care provider survey.

**Parent survey.** Parental factors affecting youth mental health service utilization were selected based on both the Gateway Provider Model and the Children's NEM. The format of the survey, along with some content, was developed specifically for use in the

current study. Below are descriptions of the variables assessed within the parent survey.

See Appendix B for the parent survey.

***Parent and child predisposing characteristics.*** Predisposing characteristics, within this framework, are defined as individual factors that may be linked to efforts to obtain mental, emotional, or behavioral health treatment. These include demographic questions regarding parent and child age, parent and child ethnicity, parent education level, and type of medical insurance coverage, if any.

***Child's level of need.*** Need characteristics were assessed through parental completion of the Pediatric Symptom Checklist (PSC; Jellinek, Murphy, & Burns, 1985). The PSC includes a total of 35 symptoms that parents indicate as happening *several times a year, once a month or more, weekly, or never*. Parental responses indicating high levels of symptoms, as well as higher frequency of symptoms, indicate need for clinical assessment (Murphy & Jellinek, 1988). Psychometric properties for this measure were established on a sample of 300 parents of youth aged 6-12. The test-retest reliability over four weeks for lower to middle-class children was  $r = .87$ ; for middle to upper-class children, it was  $r = .85$  (Murphy et al., 1988). Parental occupation was used to assess socioeconomic status. The authors used in-depth interviews with both children who had high and low scores on the PSC, by child psychologists who were blind to the child's PSC score, to test convergent validity. PSC scores aligned with clinical consensus 79% of the time, for both white children and children of color (Murphy et al., 1988). In the current sample the PSC was found to have reliability of  $\alpha = .94$ . See Appendix C for the PSC measure.

In addition to the PSC, parents were asked if they had previously accessed emotional and/or behavioral health care for their child. Parents indicating yes were asked to provide information on the pathway to care and of what the treatment consisted. Parents indicated their agreement to statements (4-point Likert scale; 1 representing *strongly disagree* and 4 representing *strongly agree*) such as “My child was referred to a mental health specialist” and “The mental, emotional, or behavioral treatment involved the use of medication.” Questions regarding pathways to care were developed specifically for the current study. See Appendix B for the parent survey.

***Enabling characteristics.*** Within this framework, enabling characteristics are defined as systemic factors that may be directly impacting efforts to obtain mental, emotional, or behavioral health treatment. Questions assessing potential enabling characteristics, such as availability, accessibility, and stigma were adapted from Larson et al. (2013). The original survey consisted of three subscales: tangible barriers, intangible barriers, and parental perception of child functioning. The original survey was administered to 55 parents of children aged two to 17 who had received a referral from the child’s pediatrician to a mental health specialist. The authors’ sample was predominately African American (98%) and a majority of referred children were school-aged (69%). Each subsection showed differing reliabilities;  $\alpha = .75$  for the nine item tangible barriers subscale,  $\alpha = .82$  for the 12 item intangible barriers scale, and  $\alpha = .73$  for the three child functioning items. For the current study, questions from both barrier subscales were utilized to assess the enabling characteristics of parents who indicated that their child needed mental health treatment but had not yet accessed such treatment.

Specifically, parents indicated how much of a problem specific barriers were to accessing services for their child (on a 3-item Likert scale where 1 represents *not a problem* and 3 represents *medium to huge problem*). Additionally, parents in this subgroup were asked to indicate their agreement (4-point Likert scale; 1 representing *strongly disagree* to 4 *strongly agree*) to statements regarding stigma and perceptions of care.

***Community perceptions of child mental health care.*** If parents indicated that they had not previously accessed services and their child had not experienced emotional or behavioral problems, they were directed to part four of the survey. This section of the survey was developed specifically for the current study. Parents in this subgroup indicated their agreement (4-point Likert scale; 1 representing *strongly disagree* and 4 representing *strongly agree*) with items related to perceptions of mental, emotional, and behavioral treatments, knowledge of local resources, and stigma. This served as a measure of community network stigma.

***Parent beliefs regarding psychotropic medications.*** Psychotropic medication literacy was also assessed in all parents, regardless of subgroup. An adapted form of a questionnaire developed by Lazaratou, Anagnostopoulos, Alevizos, Haviara and Ploumpidis (2007) was used. The original questionnaire featured 20 items assessing parents' beliefs and perceptions regarding psychotropic medications. The current study adapted this questionnaire to feature 19-items, eliminating one item that was redundant with another question. All questions were reworded to a seventh grade reading level to assess parents with a wide range of educational backgrounds. Items consist of both yes/no

and multiple choice questions. See Appendix D for the psychotropic medication questionnaire.

### **Procedure**

The HSU IRB approved the study (#15-211). Primary care providers were recruited through several methods including conference and community meeting attendance, email invitation, and snowball sampling. Two medical societies and one physicians' association agreed to distribute the survey link to all members on their listserv. Through these three organizations, physicians and other medical professionals in all six counties were invited to participate. Additionally, recruitment took place at a local pediatric mental health conference and meetings of a community coalition for professionals providing services to families with young children, by sharing a description of the project and distributing the survey link. Once primary care providers opened the online link, consent forms were administered and electronically signed. See Appendix E for the provider consent form.

Parents were recruited through schools which agreed to distribute the survey. Over a three month period, the principals of schools located in the six counties were emailed a brief description of the study and asked if they would agree to have the survey sent home to parents. At the end of the recruitment period, ten principals in four counties agreed to distribute the survey. Of these schools, six are located in Humboldt county, two in Trinity county, and one each in Del Norte and Siskiyou counties.

Two principals determined that an email invitation was preferred to paper surveys. The other eight received a total of 1,392 survey packets to distribute to parents. Packets contained a cover letter with an online survey link for parents who preferred this method of completing the survey. Parents completing the paper version also received a postage-paid envelope in which to return the survey. Parents were then presented with an informed consent either digitally or within the packet to sign and return. See Appendix F for the parent consent form. Forty-four parents returned a paper survey and 21 elected to complete the survey online. Parents who completed the paper format did not differ from parents that chose to complete the survey online by gender ( $p = .09$ , *Fisher's exact test*), race/ethnicity ( $p = .86$ , *Fisher's exact test*), education level ( $p = .13$ , *Fisher's exact test*), marital status ( $p = .43$ , *Fisher's exact test*) or employment ( $p = .15$ , *Fisher's exact test*). Additionally,  $t$  test analysis indicated that groups did not differ in age,  $t(60.18) = 0.61$ ,  $p = .54$ ,  $d = 0.13$ .

## Results

### Descriptive Sample Results

**Primary care provider demographics.** Primary care providers were predominately female (77.8%) and white (61.1%). Most providers reported their medical title as MD/DO (83.3%) and many worked in a community clinic practice (44.4%). Less than half of providers indicated that they had received continuing education training related to developmental or behavioral pediatrics (47.4%), while 36.8% reported no specialized training (see Table 1).

**Parent demographics.** Parent participants were predominately female (82.8%) and white (63.5%). Over half of parents indicated that they had a college level education (53.2%). Additionally, 65.1% of parents reported being married (See Table 2).

**Parent-reported child demographics.** The majority of children resided in Humboldt County ( $N = 35$ ) followed by Del Norte County ( $N = 22$ ). Trinity and Siskiyou Counties had fewer respondents ( $N = 4$  and  $N = 1$ , respectively; see Table 3). Over two thirds of the 22 parents residing in Del Norte County reported their children have experienced mental, emotional, or behavioral health problems. Over half of the 35 parents in Humboldt County reported that their children have experienced mental health challenges. Additionally, two of the four parents in Trinity County, and the single respondent in Siskiyou County reported that their children have struggled with such difficulties.

Children in all counties most often had health insurance coverage supplied by Medi-Cal/Partnership HealthPlan (PHP; 51.6%). Thus, many families sampled are of low income. Few children across all counties (4.8%) were reported to have no health insurance coverage.

Parental subgroups did not differ by gender ( $p = .63$ , *Fisher's exact test*), race/ethnicity ( $p = .32$ , *Fisher's exact test*), insurance coverage ( $p = .19$ , *Fisher's exact test*), or county of residence ( $p = .64$ , *Fisher's exact test*). Additionally, analysis of variance indicated that subgroups children did not differ in mean age by group,  $F(2, 57) = 1.30$ ,  $p = .28$ ,  $\eta^2 = .04$ .

**Parent-reported child mental health symptoms.** All parents completed the Pediatric Symptom Checklist (PSC). The range of scores for the sample was zero to 64, with a mean overall score of 27.8 ( $SD = 16.1$ ). Children who score 28 or above on the PSC are recommended to be referred for further evaluation (Murphy & Jellinek, 1988). Mean PSC scores in the current sample varied by group  $F(2, 57) = 11.54$ ,  $p < .001$ ,  $\eta^2 = .32$ . "In need" children scored significantly higher on the PSC ( $M = 38.5$ ,  $SD = 9.3$ ) when compared to the "client" subgroup ( $M = 33.9$ ,  $SD = 16.9$ ), and "comparison" subgroup ( $M = 18.4$ ,  $SD = 12.0$ ). Additionally, "client" children's mean PSC score was significantly higher than comparison children. This suggests that children presenting with the greatest number of symptoms were not receiving treatment and that treatment access may reduce symptoms.

Table 1. Primary Care Provider Demographics ( $N = 19$ )

<b>Demographic Variables</b>	<b><i>n</i></b>	<b>%</b>
<b>Race/Ethnicity</b>		
Native American	2	11.1
Asian American	1	5.6
African American	1	5.6
Hispanic/Latino(a)	2	11.1
White	11	61.1
Biracial/Multiracial	1	5.6
<b>Gender</b>		
Male	4	22.2
Female	14	77.8
<b>Degree Type</b>		
MD/DO	15	83.3
Registered Nurse	1	5.6
Physicians' Assistant	1	5.6
Public Health Nurse	1	5.6
<b>Practice Type</b>		
Community Clinic	8	44.4
Group Practice	6	33.3
Other	4	22.2
Community Clinic & Hospital		
Community Clinic, Hospital & Private Practice		
IHS Tribal Clinic		
Public Health		
<b>Specialized Training in</b>		
<b>Developmental/Behavioral Pediatrics</b>		
Rotation	2	10.5
Fellowship	1	5.3
Continuing Education	9	47.4
None	7	36.8
<b>Age</b>		
Range		32 – 69
Mean (SD)		47.2 (11.7)

Table 2. Parent Demographics ( $N = 65$ )

<b>Demographic Variables</b>	<b><i>n</i></b>	<b>%</b>
<b>Race/Ethnicity</b>		
Native American	8	12.7
Asian American	2	3.2
African American	0	0.0
Hispanic/Latino(a)	3	4.8
White	40	63.5
Biracial/Multiracial	10	15.9
<b>Gender</b>		
Male	11	17.2
Female	53	82.8
<b>Education Level</b>		
No Formal Education	1	1.6
Finished High School	9	14.1
Some College	20	31.2
College Degree	25	39.1
Graduate Degree	9	14.1
<b>Marital Status</b>		
Married	41	65.1
Single	6	9.7
Cohabiting	5	7.9
Separated	4	6.3
Divorced	4	6.3
Widowed	2	3.2
Other	1	1.6
<b>Employment Status</b>		
Not Employed	12	18.8
Part-time	10	15.6
Full-time	36	56.2
Other	6	9.4
<b>Age</b>		
Range		29 - 86
Mean (SD)		42.1 (9.4)

Table 3. Parent-Reported Child Demographics ( $N = 65$ )

<b>Demographic Variables</b>	<b><i>n</i></b>	<b>%</b>
<b>Race/Ethnicity</b>		
Native American	7	11.5
Asian American	2	3.3
African American	0	0.0
Hispanic/Latino(a)	2	3.3
White	32	52.5
Biracial/Multiracial	18	29.5
<b>Gender</b>		
Male	38	61.3
Female	24	38.7
<b>County of Residence</b>		
Humboldt	35	56.5
Del Norte	22	35.5
Trinity	4	6.5
Siskiyou	1	1.6
<b>Insurance Coverage</b>		
Private/Employer	25	40.4
Medi-Cal/Partnership HealthPlan (PHP)	33	51.6
United Indian Health	2	3.2
No Coverage	3	4.8
<b>Number of Siblings</b>		
Range		0 – 6
Mean ( <i>SD</i> )		1.7 (1.3)
<b>Age</b>		
Range		29 - 86
Mean ( <i>SD</i> )		42.1 (9.4)

## **Provider Results**

**Provider-reported practice demographics.** Providers estimated that an average of 44.2% of the children for which they are the primary care provider are European-American, followed by Native American and Hispanic (27.8% and 24.4%, respectively). Nearly three-fourths of their patient panel are insured through Medicaid/CHIP, indicating that physicians serve a largely low income community.

**Organizational factors.** Many organizational factors may impact gateway providers' perceptions and knowledge about youth mental health and in turn influence treatment decisions. In the current study one organizational factor assessed was providers' level of burden, defined though caseload, as well as prevalence of mental health challenges among their youth patients. Additionally, providers' workplace culture and climate, which relate to normative practices, were measured through providers use of reliable socioemotional assessments and screens and use of other diagnostic tools.

**Providers' level of burden.** Providers serve an average of 431 children in their practices. Providers reported the number of youth in their patient panel ranged from one child to as many as 2,500. The most commonly reported number of youth in primary care providers panel was 200. Providers estimate that an average of 35.4% of the children and adolescents they serve have an emotional, mental, or behavioral health problem.

The frequency of specific conditions observed by providers in youth patients varied. One-third of providers indicated that they had encountered ADHD in 30 or more patients within the past 12 months. Sixty percent of providers reported encountering

depression and 50% reported observing anxiety in a dozen or more youth patients within the past year. All specific conditions assessed were seen by providers in at least one youth patient in the previous year.

*Assessment and diagnostic tools used.* The Patient Health Questionnaire-9 (PHQ-9; Korenke et al., 2001) was the only reliable assessment measure reportedly used *nearly always* by any provider, with 35.7% of providers reportedly using the PHQ-9 *regularly*. The Child Behavior Checklist (CBCL; Achenbach, 1994) and the Child Depression Inventory (CDI; Kovacs, 1985) were the only other reliable assessment measures used *regularly* by 28.6% and 21.4% of providers, respectively. The remaining assessment instruments listed on the measure were *never* used by at least 64.3% of providers and Parents' Evaluation of Developmental Status Questionnaire (90%; PEDS; Glascoe, 2013) and Adverse Childhood Experiences Questionnaire (83.3%; ACE; Felitti et al., 1998) measures were least used.

Providers were given space to write which assessment measures they use if they were not already listed. Two providers each indicated that the Generalized Anxiety Disorder-7 and National Institute for Children's Health Quality (NICHQ) Vanderbilt Assessment are used in their practice; however, the frequency of use was not recorded. Moreover, 71.4% of providers reported the DSM as the primary diagnostic tool used, yet 92.9% reported that they do not use the tool prior to every diagnosis. Only one provider reported using a diagnostic tool prior to every new diagnosis of ADHD, depression, or anxiety.

**Primary care provider knowledge.** Providers were asked to report their comfort level in assessing and diagnosing specific conditions in youth. Depression and ADHD were the conditions for which providers indicated the most comfort (92.9% and 92.8%, respectively). The majority of providers indicated at least some comfort with assessing all nine conditions, ranging from 57.1% feeling comfortable assessing PTSD to 78.6% for anxiety.

Similarly, providers were asked about their comfort level in administering treatment to youth for the nine conditions and a similar pattern emerged. Providers reported the most comfort in treating depression, anxiety, and ADHD (71.4%). Providers felt at least somewhat uncomfortable treating the remaining seven conditions, ranging from 69.2% feeling uncomfortable treating oppositional defiant disorder (ODD) to 57.2% for autism spectrum disorder (ASD).

Finally, providers were asked to report their comfort in managing psychotropic medications without psychiatric consultation. Nearly all providers indicated comfort in managing both SSRIs (100%) and stimulant medications (91.7%). In contrast, 77.7% of providers reported being uncomfortable managing antipsychotics, 77.7% were uncomfortable managing atypical psychotropic medications, and 75% were uncomfortable managing polypharmacy.

Eighty-one percent of providers were aware of community mental health resources, yet only 43.8% reported having access to mental health agencies or providers with whom they could consult. Additionally, only 21.4% indicated that their practice already has a specialist present. Moreover, 78.6% indicated that they did not have such

access but believed it would be beneficial to have a mental health specialist on-site. Also, 93.3% of the sample reported having difficulty accessing mental, emotional, or behavioral health services for youth patients. Providers (93.8%) reported that parents would have similar difficulties trying to locate and access services.

Over one third of the sample indicated that having too little time was a barrier to the assessment and identification of mental, emotional, or behavioral health problems in youth. Additionally, 42.1% of providers reported too little time as a barrier to providing guidance or counseling themselves, followed by having insufficient knowledge (36.8%). Lack of knowledge was reported by 42.1% of providers as a barrier to initiating medication to treat a mental health problem. Finally, a lack of available specialists was the most commonly reported barrier to referring youth patients to both a psychiatrist or psychologist (68.4% and 63.2%, respectively).

**Primary care provider treatment decisions.** ADHD was the only condition for which medication was the most likely treatment (85.7%). For all remaining disorders, providers indicated that the most likely treatment would be a referral to a psychologist or agency, ranging from 74.6% for ASD to 100% for both ODD and substance abuse. In each of these cases, referral to a psychiatrist was reported as the second most likely treatment, ranging from 53.9% for both ASD and anxiety to 77% for eating disorders.

Providers were asked to indicate actions they had taken with youth patients in the past six months. Thirty seven percent of providers reported that for each ASD, eating disorders, and ODD they most commonly referred children to a mental health specialist or agency. Only 10.5%, 15.8%, and 5.3% of providers reported prescribing medication

for ASD, eating disorders, and ODD respectively. Additionally, only 5.3% of providers reported prescribing medication for substance use disorders in youth. Over half of providers indicated that prescribing medication was the most common treatment for ADHD. Additionally, 47.4% of providers reported providing further assessment themselves as the most common action taken for ADHD. Approximately one third of providers indicated that they have referred youth to a mental health specialist for all conditions and 42.1% of providers referred children suffering from anxiety. Interestingly, 42.1% of providers reported consulting with a mental health care provider and providing counseling themselves as the most commonly taken actions for youth presenting with depression.

These results suggest that although primary care providers indicate that they would likely refer youth struggling with most mental health problems, they often provide further assessments themselves or prescribe medications, particularly for ADHD, depression, and anxiety. Additionally, these were also the conditions with which providers were the most comfortable diagnosing and treating.

## **Parent Results**

**Child's level of need.** All parents were asked if their child had received mental, emotional, or behavioral health treatment. Those parents who responded yes ( $N = 24$ ) gave information regarding the pathway to care and of what treatment consisted. There was a range of time frames during which their child's treatment took place, from one month to five years ago, and five parents reported that their children were currently

receiving treatment. There was a range of time periods for which symptoms existed before the child accessed treatment, from months to several years, with an average of 26 months before treatment was accessed. Additionally, most “client” parents ( $N = 17$ ) reported that their child was currently experiencing difficulties.

The majority of “client” parents (68.4%) reported that their child’s emotions and behaviors interfere with friendships, family relationships, and school achievement, may negatively impact their child’s future (78.9%), and cause stress in their lives (78.9%).

Sixty-five percent of client parents stated that their child’s primary care physician was the first professional they approached with their concerns. Parents indicated that their child’s primary care provider confirmed that their child had a problem (57.9%) and over half of client parents felt that the provider understood their child (52.9%).

Overall, psychotropic medication was involved in half of the mental, emotional or behavioral health treatments reported by client parents. Interestingly, of all client parents who indicated that their child’s physician defined the problem, 72.7% reported that medication was involved in treatment. Furthermore, all client parents that indicated medication was used in their child’s treatment also endorsed that their child’s problem behaviors, thoughts, and emotions were causing stress in their lives.

Slightly more than half of parents (55%) indicated that the physician referred their child for treatment. Unfortunately, only 45% of client parents felt that the treatment their child received helped to abate the problem. Of the parents who reported their child’s treatment as unsuccessful, only 27.3% indicated treatment was administered by a mental health professional.

The above results, in conjunction with 65% of client parents indicating that their child was experiencing mental health symptoms at the time of the survey, suggest that treatments youth are receiving are not generally perceived as successful by parents. However, most client parents (94.7%) believed that their child's difficulties could be reduced through participation in mental health treatment. This suggests that treatments provided by those other than mental health professionals were not considered by parents to be effective mental health treatment.

**Enabling characteristics.** Parents who answered yes to their child having problems but not receiving treatment ( $N = 15$ ) reported on barriers they had experienced in accessing services for their child. Many "in need" parents (68.7%) reported that the problems experienced by their child were severe enough to warrant treatment, but 81.3% stated that they were unaware of where to go to initiate treatment. Additionally, 37.5% of parents in need reported not knowing how to make an appointment, not having access to childcare for their other children, and that the mental health provider was located too far from their home. One third of in need parents indicated that they were unsure of what to expect at a mental health appointment and that there were other things going on in their lives to prevent treatment access. Few parents (6.2%) indicated that they would feel embarrassed if their family or friends knew their child received mental health treatment.

Similar to client parents, most in need parents (73.3%) reported that their child's behaviors and emotions were causing difficulty at school and with friends, may negatively impact the future (87.5%), and cause stress in their lives (75%). Also, most

parents in need (93.8%) believed that their child's problems would be helped with access to mental, emotional, or behavioral health treatment.

**Community knowledge and perceptions.** Parents who responded no to questions regarding both previous mental health treatment and the experience of mental, emotional, or behavioral health problems ( $N = 26$ ) served as a comparison group that may reflect general community perceptions surrounding mental health care. Most comparison parents (80.7%) indicated that they were aware of the community's mental health resources yet 77% reported that they would initially bring their child to see a primary care provider should they develop psychosocial difficulties. Nearly all comparison parents (96%) indicated that if their child needed mental health treatment, they would have the resources needed to access services and would have the support of their family and friends. Very few comparison parents (8%) reported that they would feel embarrassed if those within their social network discovered their child was receiving treatment for a mental, emotional, or behavioral health problem. As was seen with the previous subgroups, nearly all comparison parents (92%) reported that they believed mental health treatment would help their child overcome challenges, should they arise in the future.

**Parent psychotropic medication literacy.** Beliefs and knowledge regarding psychotropic medication were assessed in all parents, regardless of subgroup. Thus, results are reported on the entire sample ( $N = 65$ ). Many parents indicated that they believed that psychotropic medication acted therapeutically (59.3%) and affected the brain, correcting a biological abnormality that is the cause of the problem (57.4%).

However, 67.7% of parents reported that the long-term use of these medications could lead to damage (i.e. to liver, kidney, and other internal organs).

Parents commonly reported having insufficient knowledge regarding many of the questions asked, ranging from 21.3% lacking knowledge regarding preferring of medication treatment over therapy, to 53.3% regarding believing physicians prescribe unnecessarily high doses. Similarly, the majority of parents (51.7%) reported being unsure if higher doses of psychotropic medication were more effective than lower doses. Regarding ADHD, depression, and anxiety, many parents indicated that they believed a combination of both medication and therapy would be the most effective treatment (50.8%, 63.8%, and 56.7%, respectively).

Additionally, parents were asked to indicate which, if any psychotropic medications they believed were likely to cause addiction and which they believed to be dangerous. Twenty percent of parents indicated that they believed all psychotropic medications may cause addiction. When specific types of medications were examined, results indicated that approximately one third of parents believe that both stimulant and antianxiety medications are most likely to lead to addiction. Examining parental opinions regarding the safety of these medications more broadly revealed that 88.7% of parents reported that they believed psychotropic medications were dangerous. Many parents indicated that all psychotropic medications were dangerous (42.4%), followed by antidepressants (19.7%), stimulants (18.3%), and antipsychotic medications (18%), specifically.

Over half of the parents surveyed believe that these medications may cause more damage to children in specific developmental stages. When asked to specify what was feared most about these medications being prescribed to children, parents indicated the potential for physical damage (45%) and the likelihood of future problems developing due to early psychotropic medication use (41%). Moreover, 37.7% parents reported that they were concerned about psychotropic medications being used excessively and not addressing the true cause of the problem (40%).

The above results suggest that many parents, while cautious about psychotropic medication use among youth, are mostly uninformed regarding their effectiveness, safety, and the biological mechanisms by which they work.

*Client parents' psychotropic medication literacy.* As stated above, half of client parents ( $N = 11$ ) indicated that their child's treatment included medication. Thus, these client parents' knowledge and beliefs regarding psychotropic medications were compared to the total sample of parents. Many of the responses exhibited similar trends with the total sample; however, there were several items on which client parents' responses were different from those of other parents in the sample.

Interestingly, no client parents' children with medication treatment indicated that therapy only would be the most effective treatment for either ADHD or depression, while 22.4% and 17.5% of the total sample of parents, respectively, believed therapy alone would be most effective. Similarly, 37% of all sampled parents reported believing that psychotropic medications create drowsiness without curing the problem, while no parents of children receiving medications indicated this response. Likewise, only 4.5% of client

parents with children taking medication reported believing that physicians prescribe too high of doses.

The above results indicate that parents may not pursue additional forms of treatment once they have received psychotropic medication treatment for their child's difficulties. Additionally, as with parents' in the total sample, client parents are largely unknowledgeable regarding many aspects of these medications.

## **Discussion**

The current study adds to the literature on primary care providers in rural areas who serve as gateway providers to youth in need of mental health services. The present findings help to illuminate the interplay between complex networks that contribute or act as barriers to service utilization for children and adolescents experiencing a mental health challenge.

### **Prevalence of Mental, Emotional, and Behavioral Health Problems**

The Gateway Provider Model details both workplace climate and culture, in addition to levels of burden, as the organizational characteristics that may influence primary care providers' perceptions and knowledge about youth mental health care (Stiffman et al., 2004). The results of the current study suggest that youth struggling with mental, emotional, and behavioral health problems are common in primary care. Rural primary care providers' average estimate of their child and adolescent patients experiencing a mental health challenge (35.4%) is higher than what is seen among youth in the general population (20%; NIMH, 2016). When examining parent responses, 60% of all parents indicated that their child has dealt with a mental, emotional, or behavioral health problem, nearly double that of provider estimates. These results may support previous research findings that mental, emotional, and behavioral health problems are more prevalent in rural areas than in large metropolitan areas (Robinson et al., 2016).

It is possible that more children in providers' patient panels experience mental, emotional, or behavioral health problems; however, providing care to an average of 431 youth, socioemotional challenges may also be overlooked. Providers reported as few as one child to as many as 2,500, with three providers indicating over 1000 pediatric patients under their direct care. These rates do not include providers' adult patients, so most of the medical providers surveyed have extremely large caseloads. Past research investigating physician caseload and burden suggest that with large patient panels, time constraints limit the preventative services they are able to provide (Altschuler, Margolius, Bodenheimer, & Grumbach, 2012; Yarnall, Pollak, Ostbye, Krause, & Michener, 2003). Patient caseloads and the prevalence therein of mental health challenges are some of the organizational characteristics considered by the Gateway Provider Model. Other organizational factors such as the use of the DSM-5 and reliable assessment measures, will be discussed in more detail next. These factors are important to consider due to their influence on an organization's ability to adopt new policies, as well as the ability to motivate members of the organization to adapt to new protocols (Glisson, 2002).

### **Organizational Impacts on Providers' Perceptions**

Factors such as caseload and burnout may directly influence providers' treatment recommendations; however, broader organizational characteristics may have an indirect influence.

The American Psychiatric Association (APA), through the publication of the DSM-5 shapes the culture surrounding the diagnosis and treatment of mental disorders.

The DSM-5 informs evaluation of mental health symptoms and clinical diagnosis and grounds research (Maser et al., 2009; Merikangas et al., 2010; Whooley, 2014).

Unfortunately, the DSM has many documented limitations, including, but not limited to, unsound scientific validity, which is demonstrated partly through high rates of comorbidity between disorders, especially among youth (Caron & Rutter, 1990; Freeman et al., 2016; Hyman, 2010; Egger & Angold, 2006). Such limitations must be critically evaluated by the practitioners who use the manual. The present study adds to the literature by examining the use and role of the DSM in primary care.

Providers indicated that the DSM was the primary diagnostic tool used within their practice, yet few providers (7.1%) referred to this or any diagnostic tool consistently prior to diagnoses of mental health disorders. Additionally, most providers indicated that they do not administer psychosocial assessment measures to pediatric patients. When assessments were used, the measure was of the type developed for a specific disorder. For example, the three measures most frequently reported: Patient Health Questionnaire-9, Generalized Anxiety Disorder-7, and the Vanderbilt Assessment, screen for depression, anxiety, and ADHD respectively.

Recent research conducted in the field of developmental psychopathology continues to illuminate the critical role that childhood adversity and trauma may play in most DSM defined disorders, particularly those which manifest in childhood and adolescence (Perry, 2017). Therefore, the use of transdiagnostic assessments and screens for childhood adversity are key in the prevention of negative outcomes. In fact,

developmental psychopathologists recommend against using a categorical diagnostic approach at all (Beauchaine & Cicchetti, 2016).

The Child Behavior Checklist was the only dimensionally designed screen that 28.6% of primary care providers used regularly. Measures that assess child development (PEDS) and experiences of trauma (ACEs) were among the least used. These results suggest that the DSM may inform both primary care providers' perceptions and knowledge about mental health challenges, as well as direct treatment recommendations. Furthermore, primary care physicians may miss psychosocial problems in youth and in this manner, fail to act successfully as gateway providers.

The present findings suggest that primary care providers are not often engaging in universal screening for mental, emotional, or behavioral health symptoms in their pediatric patients. Additionally, measures of socioemotional development and experiences of adversity are rarely administered. Rather, when approached by a concerned parent, providers administer an assessment for a specific DSM defined mental health disorder from which they believe the child is suffering. The DSM supports a medical model approach to treatment which often leads to the prescription of psychotropic medications, specifically in primary care. In this way, the DSM-5 influences primary care providers' decisions regarding treatment.

If a child presents with symptoms on a screen for ADHD, the primary care provider, who has little formal training in behavioral pediatrics (Smith et al., 2014), will likely take the results of the single evaluation as evidence for the presence of ADHD. Due to providers consistently reporting high levels of comfort in treating ADHD (Pidano

et al., 2011; Pidano et al., 2014) and managing stimulant medications (Anderson et al., 2015; Galéra et al., 2014), this is often likely the treatment recommendation, a pattern supported by the current findings.

The prevalence of mental, emotional, and behavioral health difficulties among youth reported by both providers and parents indicate that the primary care provider will likely remain an authority to whom parents turn with concerns regarding their child's problematic thoughts, emotions, or behaviors. Unfortunately, current results suggest that providers are not systematically screening for these difficulties and may not have the training or time needed to thoroughly assess socioemotional development in their youth patients. Beyond identification and assessment, many primary care providers reported taking treatment actions such as prescribing medication or managing problems themselves. Primary care providers' treatment actions and parents' satisfaction will be explored more in depth below.

### **Mental Health Treatment for Youth in Primary Care**

The majority of client parents reported primary care physicians as the first professional approached regarding concerns over their child's problems. Additionally, 76% of parents in the comparison subgroup indicated that their child's healthcare provider would be their initial contact should problems develop in the future. These findings support the Gateway Provider Model in which primary care physicians play a significant role in youths' pathway to care (Stiffman et al., 2004).

Over half of client parents indicated that their child's primary care provider confirmed their belief that their child had a problem. Of these client parents for whom providers defined the problem, 72.7% indicated that psychotropic medication was involved in their child's treatment. Similarly, Anderson et al. (2015) found that 70.2% of children seen by a primary care provider for any mental health problem were prescribed medication. These results demonstrate the way in which organizational characteristics, such as use of the DSM and limited time or training for assessment, may impact providers' perceptions of both symptom presentation and effective treatment options. Due to providers' lack of specialized knowledge regarding the treatment of emotional, behavioral, or mental health problems (Smith et al., 2014), as well as a lack of time (Pidano et al., 2011), primary care providers' ability to comprehensively assess symptomatic youth may be limited.

When examining primary care providers' assessment and treatment patterns, ADHD, depression, and anxiety were the conditions with which providers felt most comfortable. Previous research conducted in urban areas found similar trends among primary care providers (Pidano et al., 2011). However, providers in the present sample indicated higher levels of comfort with all three conditions. Providers reported encountering ADHD, anxiety, and depression most often in their youth patients. Provider comfort with diagnosis and treatment was similarly high for ADHD, depression, and anxiety. Finally, providers felt most comfortable managing, SSRIs and stimulant medications, supporting nationwide trends (Jonas et. al., 2013). This finding may suggest that providers practicing in rural communities may be called upon to assess and treat

mental health challenges in children more regularly than urban primary care providers and therefore, report more comfort. Segool et al. (2013) found that pediatricians practicing in small metropolitan regions (<20,000 residents) were more likely to supply mental health treatment than physicians in larger urban areas.

In the current study, at least one provider reported that they would provide further assessment, prescribe medication, or give counseling without medication. This result held true for conditions that providers indicated they were the least comfortable treating, such as ODD, PTSD, and substance use disorders. These findings support claims that primary care providers who perceive fewer community mental health resources often are more likely to initiate treatment themselves (Dempster et al., 2015). Therefore, it is critically important to build provider knowledge of available community mental health resources, as well as knowledge of the process through which parents must navigate to secure an appointment for their child.

The current results highlight that primary care providers are positioned to be key gateway providers, particularly in rural areas. Providers reported observing mental health symptoms in over one third of their child and adolescent patients. However, results suggest that while youth presenting with symptoms are common, providers are not often screening for mental health challenges, developmental milestones, or trauma. Assessments administered were most often for a single discrete disorder, as opposed to more holistic evaluations. Moreover, the assessments are typically for disorders which medications are first line treatment, such as ADHD, depression or anxiety (Olfson et al., 2014; Rynn et al., 2011). Due to the lack of longitudinal studies on both long term use

and effectiveness of medications among youth (Thomas et al., 2013), this form of treatment must be examined closely, particularly within primary care settings in rural communities, where their use is more common (Anderson et al., 2015; Segool et al., 2013).

**Treatment with psychotropic medication.** Results from the current study indicate that psychotropic medication was a part of treatment for 50% of those who had received treatment ( $N = 23$ ). Though not directly measured, results regarding providers' large caseloads, as well as parent stress suggest that children receiving these types of medications are likely not re-assessed by providers as consistently as is recommended by the FDA (Rynn et al., 2011). Although sample size limited the inferential statistical analyses that could be conducted, frequency tables revealed that of those children who received medication ( $N = 10$ ), most were male ( $N = 7$ ) and half were insured through Medicaid/PHP ( $N = 5$ ). This supports previous findings that being male and having health insurance through Medicaid/CHIP may increase the likelihood of being prescribed psychotropic medication (Galéra et al., 2014; Howie et al., 2014). However, the current study's findings should be interpreted with caution as 75% of children insured through these programs ( $N = 15$ ) did not receive medication as part of treatment.

Results from the current study suggest that while parents may be cautious regarding the use of psychotropic medications with children, many view them as a viable form of treatment, correcting a biological abnormality. Additionally, many parents indicated that for some of the most common conditions seen among youth (ADHD, depression, and anxiety) both the use of medication and therapy would be most effective.

However, no parents of children on psychotropic medication believed that therapy alone would be an effective treatment. Together, this supports the claim that often psychotropic medications are viewed as first line treatment, as opposed to being reserved for the most severe mental health symptoms (Rynn et al., 2011). Unfortunately, parents are unaware that medication effectiveness for youth has often not been demonstrated empirically and few studies have investigated long-term use (Christian et al., 2015; Ruggiero et al., 2012; Thomas et al., 2013).

Most client parents who indicated that psychotropic medication was used in their child's treatment also indicated that their child's primary care provider stated there was a problem and all indicated that their child's impairments were causing stress in their lives. Cormier (2012) similarly found that prior to parents' decision to begin medication treatment for their child's mental health problems, high levels of stress were felt within the family. Together, these results suggest that parents often follow the authority of professionals regarding the most effective treatments for their child's difficulties, particularly when they experience stress or pressure from others.

The above results highlight the limitations of providing youth with mental health treatment solely within the context of primary care. When providers perceive a mental health condition as one for which psychotropic medication is a viable treatment option, they often forego a more thorough assessment. The consequences of this are twofold: the child or adolescent may have different or multiple sociocontextual issues that are left unaddressed and they may be exposed unnecessarily to psychotropic medications.

Therefore, it is important to understand the barriers that providers and parents face when attempting to obtain mental health services for youth.

### **Barriers to Mental Health Service Utilization**

Providers indicated that a lack of time was a common barrier to administering assessments for psychosocial difficulties in pediatric patients, as well as for counseling or providing guidance to patients themselves. Given the large number of patients under the care of the physicians sampled, having too little time to address problems in youth is expected. The current results indicate that primary care providers' lack of knowledge regarding psychosocial problems is also a barrier to them providing guidance themselves. Similar barriers have been reported by primary care providers in previous research (Dempster et al., 2015; Pidano et al., 2011; Pidano et al., 2014).

Parents in need of services for their child most often cited tangible barriers as the most challenging. These barriers included not having child care for their other children and the provider being located too far from their home. These results contrast with previous research conducted on urban samples which found that tangible barriers were unrelated to treatment access; however, intangible barriers, such as stigma and negative beliefs regarding mental health care were related to underutilization (Larson et al., 2013). Such discrepancies with past research may be due to several reasons, such as parents living in urban areas having greater community resources, like access to reliable public transportation. Additionally, most in need parents in the current sample perceived their child's difficulties as severe enough to warrant treatment. This finding is divergent from

previous findings which reported that urban parents who failed to attend a mental health appointment to which their child was referred were often unsure whether their child needed treatment (Brown et al., 2014). The difference with the current study findings may also be due to urban parents' ability to gain access to a gateway provider in a shorter range of time after developing concerns regarding their child's problematic behaviors or emotions, as compared to rural parents. In the current sample, rural parents reported waiting an average of 26 months after the development of symptoms before their child accessed services.

In the current study intangible barriers, such as parent perceptions of stigma, were not related to in need parents' inability to access services. Additionally, parents in the comparison subgroup also reported low levels of perceived stigma, suggesting, perhaps, that overall levels of stigma within the community regarding children's mental, emotional, and behavioral health treatment are low. As detailed in the Children's Network Episode Model (CNEM) stigma within the community may filter down to influence parents' attitudes regarding mental health services (Costello et al., 1998). These findings are similar to previous research which found rural parents' overall levels of perceived stigma to be low (Polaha et al., 2015). This is encouraging because stigma has been found in previous research to be a barrier to service utilization (Mukolo, Heflinger, & Wallston, 2010).

Parents and primary care providers in the current study identified the community as low income, lacking in resources, and in need. This suggests that perhaps efforts to increase service utilization should focus on tangible barriers, particularly the perceived

lack of available mental health specialists in the community, parents finding transportation and childcare, and knowing how to make an appointment and what to expect, because they are not limited by stigma or fear of treatment and would be willing to bring their children in for treatment.

Many providers lacked mental health specialists with whom they could consult regarding mental, emotional, and behavioral problems experienced by their youth patients. This is despite a sizable portion of sampled providers indicating an awareness of community mental health resources. These findings are similar to results from Pidano and colleagues (2014), that primary care providers often lack consultative relationships with mental health care specialists. Additionally, providers most often cited a lack of available specialists as a barrier to many of the tasks investigated, such as screening, providing counseling, medication management, and referral to mental health care specialists. Most providers (93.3%) indicated that obtaining services for children and adolescents experiencing mental health symptoms is difficult, for both themselves and for parents.

The current study illuminates the experiences of both rural parents and gateway providers, specifically primary care providers, regarding children's mental health care. Rural primary care providers face barriers when attempting to connect youth to mental health care treatment. When fewer resources with which to help youth are perceived, physicians may provide service themselves, instead of successfully acting as gateway providers. Nearly half of client parents reported being dissatisfied with the treatments that were received by their children. Moreover, parents in need of services most commonly reported not knowing where or how to initiate treatment. Finally, comparison parents

overwhelmingly reported that their child's physician would be their first contact should difficulties present in the future. The present findings have important implications for mental health care service delivery which will be discussed in more detail next.

### **Implications for Service Delivery**

The current results support the Gateway Provider Model. These include the idea that child and family "need characteristics" and "predisposing characteristics," gateway providers' knowledge, and more systemic characteristics, such as "enabling characteristics," and the climate and culture of the organizations for which providers work are key influences on treatment access (Stiffman et al., 2004). However, the current results suggest that characteristics which contribute to tangible barriers to service utilization may be most salient in rural communities. Large caseloads, time constraints, and lack of universal screening protocol indicate that systemic organizational factors greatly impact rural providers' treatment actions regarding youth presenting with mental health symptoms.

One key organization factor for enhancing service utilization may be to increase providers' use of reliable, dimensional assessment measures and screens that are transdiagnostic. Recent findings suggest that the use of valid psychosocial screens during primary care appointments may serve to open communication between parents and providers regarding youth mental health (Gadomski et al., 2015; Murphy, Steele, Steele, Allman, Kastner, & Dube, 2016; Pidano & Honigfeld, 2017; Ward-Zimmerman & Cannata, 2012). However, the present findings suggest that community primary care

providers are not screening universally for socioemotional difficulties, developmental milestones, or experiences of trauma.

Murphy et al. (2016) suggest that pediatric primary care provides the ideal setting in which to universally screen for ACEs, both in youth and their parents. Additionally, Gadowski et al. (2015) found that after being screened for psychosocial problems, adolescents offered more information to physicians regarding mental health concerns than youth who were not assessed.

Strategies for implementing a universal screening process without taking time from the appointment include, but are not limited to, administering assessments prior to the appointment through secure servers, or providing them to parents in the waiting room (Oppenheim, Stewart, Zoubak, Donato, Huang & Hudock, 2016). Additionally, a standardized process should be developed by practice organizations for when a child or adolescent screens positive, to ensure that a more in-depth assessment is conducted (Oppenheim et al., 2016).

Increasing communication between mental health specialists and primary care providers may help increase youth's access to mental health services (Green, Ford, Ward-Zimmerman, Honigfeld, & Pidano, 2016; Stiffman et al., 2000). Past research indicates that the more connected gateway providers are with local mental health resources, the greater the likelihood of identification and referral (Stiffman et al., 2000). Unfortunately, the current results suggest that the majority of local primary care providers do not have well-established relationships with mental health specialists with whom they can consult, or to whom they can refer youth.

Green et al. (2015) found that by increasing the frequency of communication between mental health and pediatric primary care providers, the quality of information exchanged and overall collaboration increased. Moreover, recent findings indicate that parents value the communication between physical and mental health care providers regarding their child's well-being (Greene, Ford & Ward-Zimmerman, 2015).

Finally, another potential solution may be the colocation of a mental health specialist within a primary health care facility. While this solution requires the greatest number of resources of those suggested, research indicates that it offers immense potential to increase mental health care service access for youth (Stancin & Perrin, 2014). The current results suggest that while few primary care providers have a mental health specialist on site at their practice, nearly all believed colocation would be beneficial.

Colocation offers the opportunity to address concerns regarding youth mental health without requiring parents to navigate through multiple barriers themselves. Recent findings suggest that youth both obtained and completed mental health treatment more often when referred to colocated mental health specialists than when referred elsewhere (Kolko, Campo, & Kilbourne, 2012). Mental health and primary care services that are located in the same facility provide the opportunity for physicians to personally introduce parents to specialists, which may help to initiate immediate care, as well as establish rapport between parent and specialist (Ader, Stille, Keller, Miller, Barr & Perrin, 2017; Oppenheim et al., 2016). Additionally, a recent meta analysis indicated significantly better mental health outcomes for children and adolescents receiving integrated care as

opposed to usual primary care (Rosenbaum-Asarnow, Rozenman, Wiblin, & Zeltzer, 2015).

### **Limitations and Future Directions**

The current study adds to previous work on mental health care utilization by using a rural sample, which included both primary care providers and parents from the same community. Additionally, the current study examined parent responses by subgroups defined by both their child's experiences of mental health problems or treatment (or lack thereof), illuminating differences in factors related to service utilization. Although small, the primary care provider sample may be representative of practices within Humboldt County, as there are fewer medical providers from which to sample than in other regions (1,400 county residents:1 primary care physician; County Health Rankings, 2016). Additionally, results highlight parents' knowledge (or lack thereof) regarding psychotropic medication for the treatment of mental health problems in youth, which are often the first line of treatment in primary care setting (Anderson et al., 2015).

Despite the strengths of the present study there are some important limitations. First, the current study had a low response rate from parents and therefore the parent sample may be impacted by self selection bias. A larger, more demographically diverse sample would allow for a more thorough evaluation of pathways to care navigated by parents within the community. Second, due to the exploratory nature of the current study, descriptive results must be interpreted with caution, as they may not be representative of all parents' or providers' experiences. Future research may consider more objective

measures of provider treatment decisions, such as practice referral rates and examination of medical records.

Future research may consider differences in pathways of care depending on the variety and severity of symptoms presented by youth, as well as by demographic groupings, such as gender and ethnicity. Moreover, benefit may come from investigating the specific steps parents take while attempting to access services for their child. Additionally, other service sectors identified within the Gateway Provider Model such as the education system, should be assessed for the role played in youths' access to mental, emotional, and behavioral health treatment, particularly within rural communities.

## **Conclusion**

This is the first study to concurrently measure both primary care providers and parents within the same community regarding their knowledge and perceptions of children's mental, emotional, and behavioral health care. Overall, results suggest that tangible barriers are most salient for both parents and providers in rural areas. These results underscore the importance of developing relationships between primary care providers and mental health specialists. Additionally, results suggest better communication from providers to parents is needed regarding available youth mental health resources.

Parents of children who are struggling with mental health challenges often experience stress and concern about their child's functioning. Parents often turn to their child's primary health care provider, particularly in rural areas, where there are fewer

mental health resources, as a source of authority on how to best help their child.

However, primary care providers often lack specialized training and the time necessary to conduct a thorough assessment and often prescribe psychotropic medications. Largely, parents are unaware of the lack of evidence regarding either effectiveness or outcomes from long term use of these medications.

The current study may be used to inform community stakeholders about the current gaps in care for those children and adolescents who struggle with mental health challenges. Strategies for addressing gaps in care include increasing universal screening for socioemotional difficulties and trauma in youth in primary care, strengthening the network between mental health and primary care providers in the community for both referral and consultation, and building toward colocated, coordinated physical and mental health care. Future research may use findings from the current study to further investigate the complex interaction between the many networks involved in mental health service utilization, or lack thereof.

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## Appendix A

### Pediatric Healthcare Providers Experiences with Children's Mental, Emotional, and Behavioral Health

Thank you for taking the time to complete this survey. First, we would like to get some general information about yourself and your background.

#### Demographic Information

1. Age:
2. Ethnicity:
  - a. European-American
  - b. African-American/West Indian
  - c. Latino/Hispanic
  - d. Asian-American
  - e. Native American
  - f. Biracial/Multiracial
  - g. Other
3. Gender:
  - a. Male
  - b. Female
4. County:
  - a. Humboldt
  - b. Del Norte
  - c. Mendocino
  - d. Trinity
  - e. Siskiyou
  - f. Shasta
5. Degree
  - a. MD/DO
  - b. Family NP

- c. RN
  - d. PA
  - e. Other (please specify)
6. Please indicate:
- a. Private Practice
  - b. Group Practice
  - c. Community Clinic
  - d. Hospital
  - e. Other (please specify)
7. Years in practice (post-residency or post-highest level of training):
8. If you have had any specialized training in developmental and behavioral pediatrics, please indicate:
- a. Fellowship in Developmental and Behavioral Pediatrics
  - b. Rotation in Developmental and Behavioral Pediatrics
  - c. Continuing Education (workshops/conferences)
  - d. None
  - e. Other (please describe)
9. Approximate date of most recent behavioral health related training, if any:

#### Part 1

The following questions ask for demographic details regarding your children and adolescent patients. Please use rough estimates when indicating your response.

1. Approximate number of children 4 to 17 for whom you are the primary medical provider:
2. Please indicate approximate percentages for the following groups treated by you:
  - a. African-American/West Indian
  - b. Asian-American
  - c. European-American
  - d. Hispanic/Latino
  - e. Native American
  - f. Biracial/Multiracial/Other

3. Approximately what percentage of the patients are insured by Medicaid or CHIP?
4. Of all the children and adolescents you see what percentage do you estimate has an emotional, behavioral or mental health problem?
5. Please indicate the frequency with which you encounter the following in your children/adolescent patients in the past 12 months:

<b>Disorders</b>	<b>0 patients</b>	<b>1 to 10 patients</b>	<b>11 to 20 patients</b>	<b>21 to 30 patients</b>	<b>31 to 40 patients</b>	<b>41 to 50 patients</b>	<b>&gt; 50 patients</b>
<b>Attention Deficit Hyperactivity Disorder (ADHD)</b>							
<b>Anxiety Disorders</b>							
<b>Autism Spectrum Disorder</b>							
<b>Depression</b>							
<b>Eating Disorder</b>							
<b>Oppositional Defiant Disorder</b>							
<b>Post-traumatic Stress Disorder (PTSD)</b>							
<b>Substance Abuse Disorder</b>							

Part 2

Please indicate how often you have used the following in your practice with child and adolescent patients, within the past 6 months:

<b>Assessment Tool</b>	<b>Never</b>	<b>Occasionally</b>	<b>Regularly</b>	<b>Nearly always</b>
<b>Beck Youth Inventories</b>				
<b>Child Behavior Checklist (Achenbach)</b>				
<b>Child Depression Inventory</b>				
<b>Pediatric Symptom Checklist</b>				
<b>PEDS</b>				
<b>Adverse Childhood Experiences Questionnaire</b>				
<b>PHQ9</b>				
<b>Other (Please specify)</b>				

Please rate your agreement with the following statements:

1. I am aware of mental health resources in the community.
  - a. Strongly Disagree
  - b. Disagree
  - c. Agree
  - d. Strongly Agree
  
2. There are mental health agencies or providers with whom I can consult as needed.
  - a. Strongly Disagree
  - b. Disagree
  - c. Agree
  - d. Strongly Agree
  
3. I have difficulty accessing mental health consultation or services for my child/adolescent patients when needed.
  - a. Strongly Disagree

- b. Disagree
  - c. Agree
  - d. Strongly Agree
4. Parents of my child/adolescent patients have difficulty accessing mental health services for their children when needed.
- a. Strongly Disagree
  - b. Disagree
  - c. Agree
  - d. Strongly Agree

Part 3

1. How comfortable are you with assessing for/diagnosing children and adolescent patients with the following disorders?

<b>Disorder</b>	<b>Not at all comfortable</b>	<b>Somewhat uncomfortable</b>	<b>Somewhat comfortable</b>	<b>Completely comfortable</b>
<b>ADHD</b>				
<b>Anxiety Disorders</b>				
<b>Autism Spectrum Disorders</b>				
<b>Depression</b>				
<b>Eating Disorders</b>				
<b>Oppositional Defiant Disorder</b>				
<b>Post-traumatic Stress Disorder</b>				
<b>Substance Abuse Disorder</b>				

2. Please indicate what diagnostic manual is most commonly used in assessing emotional, behavioral, or mental health problems and the capacity in which it is used:
3. Do you consult this tool prior to every diagnosis of an emotional, behavioral, or mental health problem?
  - a. Yes
  - b. No

4. How comfortable are you with providing treatment to children/adolescents with the following disorders?

<b>Disorder</b>	<b>Not at all comfortable</b>	<b>Somewhat uncomfortable</b>	<b>Somewhat comfortable</b>	<b>Completely comfortable</b>
<b>ADHD</b>				
<b>Anxiety Disorders</b>				
<b>Autism Spectrum Disorders</b>				
<b>Depression</b>				
<b>Eating Disorders</b>				
<b>Oppositional Defiant Disorder</b>				
<b>Post-traumatic Stress Disorder</b>				
<b>Substance Abuse Disorder</b>				

5. How likely are you to initiate psychotropic medication for a child/adolescent with the following?

<b>Disorder</b>	<b>Not at all likely</b>	<b>Somewhat unlikely</b>	<b>Somewhat likely</b>	<b>Completely likely</b>
<b>ADHD</b>				
<b>Anxiety Disorders</b>				
<b>Autism Spectrum Disorders</b>				
<b>Depression</b>				
<b>Eating Disorders</b>				
<b>Oppositional Defiant Disorder</b>				
<b>Post-traumatic Stress Disorder</b>				
<b>Substance Abuse Disorder</b>				

6. How likely are you to refer a child or adolescent with the following disorders to a psychologist, therapist, or a community mental health agency?

<b>Disorder</b>	<b>Not at all likely</b>	<b>Somewhat unlikely</b>	<b>Somewhat likely</b>	<b>Completely likely</b>
<b>ADHD</b>				
<b>Anxiety Disorders</b>				
<b>Autism Spectrum Disorders</b>				
<b>Depression</b>				
<b>Eating Disorders</b>				

<b>Disorder</b>	<b>Not at all likely</b>	<b>Somewhat unlikely</b>	<b>Somewhat likely</b>	<b>Completely likely</b>
<b>Oppositional Defiant Disorder</b>				
<b>Post-traumatic Stress Disorder</b>				
<b>Substance Abuse Disorder</b>				

7. How likely are you to refer a child/adolescent with the following disorders to a psychiatrist?

<b>Disorder</b>	<b>Not at all likely</b>	<b>Somewhat unlikely</b>	<b>Somewhat likely</b>	<b>Completely likely</b>
<b>ADHD</b>				
<b>Anxiety Disorders</b>				
<b>Autism Spectrum Disorders</b>				
<b>Depression</b>				
<b>Eating Disorders</b>				
<b>Oppositional Defiant Disorder</b>				
<b>Post-traumatic Stress Disorder</b>				
<b>Substance Abuse Disorder</b>				

8. Please indicate any and all actions that you have taken in the last 6 months, when child/adolescent patients struggle with the following disorders:

<b>Disorder</b>	<b>Refer to a mental health specialist</b>	<b>Consult with a mental health specialist</b>	<b>Counsel/ manage without medication</b>	<b>Prescribe medication</b>	<b>Consult with another health care provider</b>	<b>Provide further assessment myself</b>
<b>ADHD</b>						
<b>Eating Disorder</b>						
<b>Depression</b>						
<b>Autism Spectrum Disorder</b>						
<b>Anxiety Disorders</b>						
<b>Oppositional Defiant Disorder</b>						
<b>Post-traumatic Stress Disorder</b>						
<b>Substance Abuse Disorder</b>						

Part 4

Please select any and all of the following are barriers to identifying, assessing, and managing the behavioral and emotional difficulties of your pediatric patients:

<b>Treatment Action</b>	<b>Too little time</b>	<b>Insufficient knowledge</b>	<b>No or minimal reimbursement</b>	<b>Lack of available specialists</b>	<b>Concern about labeling children/stigma</b>
<b>Identify problems or disorders and screen/assess for problems or disorders</b>					
<b>Initiating medication myself</b>					
<b>Monitor medication prescribed by a psychiatric provider</b>					
<b>Provide counseling or guidance myself</b>					
<b>Refer to a psychiatrist</b>					
<b>Refer to psychologist, therapist, or mental health agency</b>					

I am comfortable managing the following medications medication on my own without psychiatric consultation:

<b>Psychotropic Medication</b>	<b>Not at all comfortable</b>	<b>Somewhat uncomfortable</b>	<b>Somewhat comfortable</b>	<b>Completely comfortable</b>
<b>Selective Serotonin Reuptake Inhibitors (SSRIs)</b>				
<b>Stimulants</b>				
<b>Anxiolytics</b>				
<b>Antipsychotics</b>				
<b>Atypical Psychotropics</b>				
<b>Polypharmacy</b>				

#### Part 6

Please answer the following questions about primary care-mental health relationships:

1. I have a formal, consultative relationship with a mental health provider.
  - a. Yes
  - b. No
  - c. Other (please specify):
  
2. It would be beneficial to have a mental health provider on-site in my practice, at least for a day or two a week.
  - a. Yes
  - b. No
  - c. My practice has a mental health specialist on-site
  - d. Other (please specify):

Please provide any other comments you wish to add about your experiences, desires, or beliefs regarding children's mental health care:

**Appendix B**

## Parent Survey on Experiences with Children's Mental, Emotional, or Behavioral Health Services

First, we would appreciate you sharing some general information about yourself.

1. Age:
2. Gender:
  - a. Male
  - b. Female
  - c. Other (please specify):
3. Ethnicity:
  - a. European-American
  - b. African-American
  - c. Asian-American
  - d. Latino/a-Hispanic
  - e. Native-American
  - f. Biracial/Multiracial
  - g. Other (please specify):
4. Education Level:
  - a. No Formal Education
  - b. Finished Grade School
  - c. Finished Middle School or Junior High
  - d. Finished High School
  - e. Some College
  - f. Finished College
  - g. Finished Grad School
  - h. Other (please specify)
5. Marital Status:
  - a. Married
  - b. Single

- c. Cohabitation with Partner
  - d. Separated
  - e. Divorced
  - f. Widowed
  - g. Re-Married
  - h. Other (please specify)
6. How many times have you been married?
7. Employment Status:
- a. Not employed outside the home
  - b. Part-time (1-34 hours)
  - c. Full-time (35 hours or more)
  - d. Other (please specify)
8. What is your current position and line of work?
9. What is your personal annual income, in thousands (not counting the income of others in your household)?

#### Part 1

Please think of only one of your children for all of the following questions, preferably a child who has experienced more difficulties in school, at home, or with friends, than other children.

1. Child's Age:
2. Child's Gender:
  - a. Male
  - b. Female
3. Ethnicity:
  - a. European-American
  - b. African-American
  - c. Asian-American
  - d. Latino/a-Hispanic
  - e. Native-American

- f. Biracial/Multiracial
  - g. Other (please specify)
4. County of Residence:
- a. Del Norte
  - b. Humboldt
  - c. Trinity
  - d. Shasta
  - e. Mendocino
  - f. Siskiyou
5. Number of siblings in home?
6. Type of health care coverage your child has

## Part 2

1. Has your child previously received mental or behavioral health treatment?  
YES  NO

If you answered No to question 1, please skip to Part 3

2. How long ago did your child receive treatment?
3. How long had your child experienced problems before seeking treatment?
4. Is your child currently experiencing mental, emotional, or behavioral health problems?  
YES  NO
5. I took my child to see a pediatrician or family doctor about these problems.  
YES  NO
6. The pediatrician or family doctor referred my child for treatment of these problems.  
YES  NO

7. Did mental, emotional, or behavioral health treatment help, did the problem subside?

YES  NO

If No, what do you think would have been more effective?

---

Please rate your agreement with the following statements:

<b>Statements</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>The doctor or nurse said my child has a problem</b>				
<b>My child was referred to a mental health specialist</b>				
<b>The doctor or nurse who referred my child to treatment understands him/her</b>				
<b>The mental, emotional, or behavioral treatment involved the use of medication</b>				
<b>My child’s emotions and behavior interferers with school, friendships, or family life</b>				
<b>My child’s emotions or behavior may affect his/her success in the future</b>				
<b>My child’s emotions or behavior cause stress in my life</b>				
<b>I believe that my child can be helped by mental, emotional, or behavioral health treatment</b>				

If your child has not received mental, emotional or behavioral health treatments please answer the following questions:

1. Your child has not received treatment but has/is experiencing mental, emotional or behavioral problems.

YES  NO

If you answered No to question 1, please skip to Part 4

If you answered Yes to question 1, please indicate how much of a problem each of these barriers are for you in receiving mental, emotional or behavioral health treatment for your child:

<b>Barriers</b>	<b>Not a problem</b>	<b>Hardly a problem or small problem</b>	<b>Medium to huge problem</b>
<b>I'm not sure where to go for treatment</b>			
<b>I'm not sure how to make an appointment</b>			
<b>There is a long wait for available appointments</b>			
<b>I'm not sure what will happen at the appointment</b>			
<b>The provider is too far from my home</b>			
<b>I'm unable to get to the appointment (transportation problems)</b>			
<b>The appointment times will not work for me</b>			
<b>I cannot miss work to bring my child to the appointment</b>			

<b>Barriers</b>	<b>Not a problem</b>	<b>Hardly a problem or small problem</b>	<b>Medium to huge problem</b>
<b>I will lose money if I miss work to bring my child to the appointment</b>			
<b>I have no one to watch my other children</b>			
<b>I have too many things going on in my life right now</b>			

Please rate your agreement with the following statements:

<b>Statements</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>My child’s problems are not bad enough to go to mental, emotional or behavioral health treatment</b>				
<b>I worry that my child will be put on medication if I go to mental, emotional or behavioral health treatment</b>				
<b>My child will not want to go to mental, emotional or behavioral health treatment</b>				
<b>I would be embarrassed if my family or friends found out I was taking my child to mental, emotional or behavioral health treatment</b>				
<b>My child’s emotions and behavior interferes with school, friendships, or family life</b>				

<b>Statements</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>My child’s emotions or behavior may affect his/her success in the future</b>				
<b>My child’s emotions or behavior cause stress in my life</b>				
<b>I believe that my child can be helped by mental, emotional, or behavioral health treatment</b>				

Part 4

If your child has not received mental, emotional or behavioral health treatment and is not experiencing problems in these areas, answer the following questions.

Please rate your agreement with the following statements:

<b>Statements</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>I am aware of mental, emotional or behavioral health treatment options in my community</b>				
<b>If my child was to experience a mental, emotional or behavioral health problem I would bring him/her to the pediatrician</b>				
<b>I have the resources to get my child to treatment if they were to experience a mental, emotional or behavioral problem</b>				

<b>Statements</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Agree</b>	<b>Strongly Agree</b>
<b>Family and friends would support me if I took my child to mental, emotional or behavioral health treatment</b>				
<b>I would be embarrassed if my family or friends found out I was taking my child to mental, emotional or behavioral health treatment</b>				
<b>I believe that my child would be helped by mental, emotional, or behavioral health treatment, if they experienced a problem</b>				

### Appendix C

#### Pediatric Symptom Checklist

Please mark how often your child experiences each symptom:

<b>Symptoms</b>	<b>Several times a year</b>	<b>Once a month or more</b>	<b>Weekly</b>	<b>Never</b>
<b>Complains of aches or pains</b>				
<b>Spends more time alone than other children</b>				
<b>Tires easily, has little energy</b>				
<b>Is fidgety, or unable to sit still</b>				
<b>Has trouble with teacher(s)</b>				
<b>Is less interested in school than other children</b>				
<b>Act as if driven by a non-stop motor</b>				
<b>Daydreams too much</b>				
<b>Is distracted easily</b>				
<b>Is afraid of new situations</b>				
<b>Feels sad, or unhappy</b>				
<b>Is irritable, or angry</b>				
<b>Feels hopeless</b>				
<b>Has trouble concentrating</b>				
<b>Is less interested in friends than other children</b>				

<b>Symptoms</b>	<b>Several times a year</b>	<b>Once a month or more</b>	<b>Weekly</b>	<b>Never</b>
<b>Fights with other children</b>				
<b>Is absent from school</b>				
<b>School grades have been dropping</b>				
<b>Is down on themselves</b>				
<b>Visits doctor, but doctor finds nothing wrong</b>				
<b>Has trouble sleeping</b>				
<b>Worries a lot</b>				
<b>Wants to be with parent more than before</b>				
<b>Feels like they are bad</b>				
<b>Takes unnecessary risks</b>				
<b>Gets hurt frequently</b>				
<b>Seems to be having less fun than other children</b>				
<b>Acts younger than children their age</b>				
<b>Does not listen to rules</b>				
<b>Does not show feelings</b>				
<b>Does not understand others' feelings</b>				
<b>Teases others</b>				
<b>Blames others for their troubles</b>				
<b>Takes things that do not belong to them</b>				

<b>Symptoms</b>	<b>Several times a year</b>	<b>Once a month or more</b>	<b>Weekly</b>	<b>Never</b>
<b>Refuses to share</b>				

**Appendix D**

## Psychotropic Medication Literacy Questionnaire

Please answer the following questions regarding your opinion on psychotropic medication.

*Note:* A psychotropic medication is a type of prescription medication that changes a persons' emotions, thoughts, or behaviors.

1. Do they act therapeutically?  
YES  NO
  
2. Do you believe that they cause drowsiness or sleepiness, but don't cure the problem?  
YES  NO  I don't know
  
3. Do you believe that psychotropics act on the brain, correcting a biological abnormality responsible for a mental, emotional, or behavioral problem?  
YES  NO  I don't know
  
4. Do you believe that by taking psychotropic medication the user will become addicted and therefore be unable to stop taking it?  
YES  NO  I don't know
  
5. If you believe that psychotropic medications cause addiction do they all, or some of them cause addiction? Which of them?
  - a. All of them
  - b. Antipsychotics
  - c. Antidepressants
  - d. Anti-Anxiety
  - e. Anti-Convulsive
  - f. Stimulants
  - g. None of them

6. What is your opinion about the use of psychotropic medication by professionals?
- They use them excessively
  - They use them only when needed
  - They don't use them enough when needed
  - I don't know
7. Do you believe that long-term use of psychotropic drugs could cause damage (e.g., on the brain, kidneys, liver, etc.)?
- YES       NO       I don't know
8. Do you believe that psychotropic drugs are dangerous? If yes, which ones?
- YES       NO
- All of them
  - Antipsychotics
  - Antidepressants
  - Anti-Anxiety
  - Anti-Convulsive
  - Stimulants
  - None of them
9. Do you think that physicians use unnecessarily high doses of psychotropic medications?
- YES       NO       I don't know
10. Do you think that higher doses are more effective?
- YES       NO       I don't know
11. Do you think that in some cases long-term use of psychotropic medication is necessary, so that the patient does not relapse?
- YES       NO       I don't know
12. Would you prefer drug treatment instead of therapy?
- YES       NO       I don't know
13. Which is your opinion about the most effective treatment for the following disorders? (circle your answer for each)

## ADHD

- a. Medication
- b. Psychotherapy
- c. Both Together
- d. I don't know

## Depression

- a. Medication
- b. Psychotherapy
- c. Both Together
- d. I don't know

## Anxiety

- a. Medication
- b. Psychotherapy
- c. Both Together
- d. I don't know

14. Do you take medication frequently? (e.g., for headaches, insomnia etc.)

YES  NO

15. Are you generally against medication?

YES  NO

16. Do you fear psychotropic medication more than other types of medication?

YES  NO

17. What do you fear most about prescribing psychotropic medication to children?

- a. They may cause damage to patient's health
- b. They get used to them easily
- c. They affect their learning abilities
- d. If they start at early ages they will have greater problems in the future
- e. They don't really fix the problem

- f. They are used excessively
- g. They are dangerous
- h. I don't fear them

18. Do you believe that the psychotropic drugs may cause more damage to children, due to their age?

YES       NO       I don't know

19. Do you think that by taking psychotropic medication from early ages they would be more likely to develop drug addiction later?

YES       NO       I don't know

**Appendix E**

**INFORMED CONSENT TO PARTICIPATE IN RESEARCH**  
HUMBOLDT STATE UNIVERSITY  
CHILDREN'S MENTAL HEALTH NEEDS ASSESSMENT STUDY  
Brandi L. Goodspeed, M.A. Candidate, Department of Psychology  
Dr. Tasha R. Howe, Professor of Psychology, Faculty Advisor

I hereby consent to complete a survey regarding my experiences involving mental, emotional, or behavioral health services for children. The study will take place during the years 2017-2018. It will take me about 30 minutes to complete the survey. The purpose of this survey is to examine providers' perceptions and experiences regarding children's mental, emotional, or behavioral health services.

I understand that neither my name nor identifying information will appear on the survey. All data will be strictly confidential and anonymous. No IP addresses will be collected in order to ensure confidentiality and anonymity. Informed consent signatures will not be linked to specific survey responses. Surveys will be used solely for research purposes only trained researchers will see the data. All data will be securely stored in a password protected data file and destroyed within three years of study completion. I may contact the researcher if I desire to know the combined study results for all participants across the six counties (my individual results will not be available as surveys are anonymous).

I understand that some questions may make me uncomfortable or may bring up emotional feelings. I am free to skip any questions I do not wish to answer.

This study will provide no direct benefit to me but will inform schools, parents, and health care providers about what is currently being done in five rural counties regarding children's mental health care provision. The goal is to begin a dialogue to improve interdisciplinary collaboration and hopefully improve access to services for children in rural areas. The only risks from taking this survey are that some questions may be uncomfortable and I need to devote 15-30 minutes to the task.

Dr. Howe is available to answer questions I have concerning this study. My participation is completely voluntary and I may withdraw from it at any time.

If I have any questions regarding the survey and/or my participation, or desire a copy of the results, I can contact Brandi Goodspeed at [blg200@humboldt.edu](mailto:blg200@humboldt.edu) or (707) 498-3934. I may also contact Dr. Tasha R. Howe at [th28@humboldt.edu](mailto:th28@humboldt.edu) or (707) 826-3759.

If you have any concerns with this study or questions about your rights as a participant, contact the Institutional Review Board for the Protection of Human Subjects at [irb@humboldt.edu](mailto:irb@humboldt.edu) or (707) 826-5165

**(PLEASE PRINT THIS PAGE FOR YOUR RECORDS)**

**Please electronically sign the next page to provide your consent.**

**Appendix F**

**INFORMED CONSENT TO PARTICIPATE IN RESEARCH**  
HUMBOLDT STATE UNIVERSITY  
CHILDREN'S MENTAL HEALTH NEEDS ASSESSMENT STUDY  
Brandi L. Goodspeed, M.A. Candidate, Department of Psychology  
Dr. Tasha R. Howe, Professor of Psychology, Faculty Advisor

I hereby consent to complete a survey regarding my experiences involving mental, emotional, or behavioral health services for my child. The study will take place during the years 2017-2018. It will take me about 30 minutes to complete the survey. The purpose of this survey is to examine parents' needs and experiences regarding children's mental, emotional, or behavioral health services.

I understand that neither my name nor identifying information will appear on the survey. All data will be strictly confidential and anonymous. All signature pages will be kept completely separate from parents' survey answers, in separate locked filing cabinets in the Developmental Psychology Laboratory at HSU. Surveys will be used solely for research purposes and only trained researchers will see the data. All data will be destroyed within three years after study completion. Online surveys will be kept in a password protected data file. No computer IP addresses will be recorded so online surveys will be completely anonymous and confidential. I may contact the researcher if I desire to know the combined study results for all participants (my individual results will not be available as surveys are anonymous).

I understand that some questions may make me uncomfortable or may bring up emotional feelings regarding my child's health. I am free to skip any questions I do not wish to answer. If I need to process these feelings, I can find a counselor or mental health service provider in my area by searching using the website URL: <https://findtreatment.samhsa.gov/> or I can call 1-877-SAMHSA-7.

This study will provide no direct benefit to me, but it will inform other parents, schools, and service providers about children's mental, emotional, or behavioral care needs in six rural counties. It is hoped that the results will start a dialogue between all concerned parties, so they can more effectively work together. This may lead to improved services

for children and families in rural areas. The only risks from taking this survey are that some questions may be uncomfortable and I need to devote 15-30 minutes to the task.

Dr. Howe is available to answer questions I have concerning this study. My participation is completely voluntary and I may withdraw from it at any time.

If I have any questions regarding the survey and/or my participation, or desire a copy of the results, I can contact Brandi Goodspeed at [blg200@humboldt.edu](mailto:blg200@humboldt.edu) or (707) 498-3934. I may also contact Dr. Tasha R. Howe at [th28@humboldt.edu](mailto:th28@humboldt.edu) or (707) 826-3759.

If you have any concerns with this study or questions about your rights as a participant, contact the Institutional Review Board for the Protection of Human Subjects at [irb@humboldt.edu](mailto:irb@humboldt.edu) or (707) 826-5165.

**(PLEASE KEEP THIS PAGE FOR YOUR RECORDS)**

**PLEASE MAIL BACK THE SIGNATURE PAGE ALONG WITH YOUR SURVEY IN THE POSTAGE-PAID ENVELOPE PROVIDED.**

**OR, IF YOU PREFER, TAKE THE SURVEY ONLINE AND ELECTRONICALLY CONSENT TO PARTICIPATE AT: [WWW.SURVEYMONKEY.COM](http://WWW.SURVEYMONKEY.COM)**

**I CONSENT TO PARTICIPATE IN THE HSU CHILDREN'S MENTAL HEALTH NEEDS ASSESSMENT STUDY.**

**SIGNATURE \_\_\_\_\_ DATE \_\_\_\_\_**