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Parent Perspectives on Community Mental Health Services for Children with Autism Spectrum Disorders

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Abstract

The community mental health (CMH) system provides treatment for behavioral and psychiatric problems in children with autism spectrum disorders (ASD). Although parent stakeholder perspectives are important to improving care, these perspectives have not been systematically examined for this population in the CMH sector. Twenty-one semi-structured qualitative interviews were conducted with parents of children with ASD who received services in CMH clinics. Themes related to child clinical histories, service access and experiences with the CMH system revealed a specific trajectory of service need identification, obtaining a diagnosis, and experience with services. Each trajectory stage was marked by high parent stress. Results provide information about the characteristics of children with ASD served in community mental health clinics and direction for targeted improvement efforts.

Keywords

Autism spectrum disorders; Parent perspectives; Community mental health services

Introduction

Children with autism spectrum disorders (ASD) may receive services in the community mental health (CMH) system for treatment of emotional and behavioral symptoms related to ASD and for a number of overlapping or co-occurring psychiatric problems that frequently occur with ASD. CMH services are designed to address psychiatric problems through psychosocial and pharmacological interventions. The current study examines the

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perspectives of parents whose children have received outpatient therapy in CMH *clinics.* Although there is significant variability in the estimated prevalence rates of co-morbid psychiatric disorders among children with ASD (Lainhart 1999), recent research suggests that approximately 70% of children with ASD meet criteria for at least one additional psychiatric disorder (Leyfer et al. 2006; Simonoff et al. 2008). These high rates of psychiatric problems for children with ASD underscore the importance of the CMH system in caring for children with ASD. A closer examination of CMH services for children with ASD is clearly indicated.

Several research-based intervention methods aimed at addressing behavioral and psychiatric problems for children with ASD have been developed and tested in controlled laboratory settings. For example, there is increasing empirical support for child skills training and parent-mediated interventions based on principles of applied behavior analysis (National Autism Center 2009; National Research Council 2001) and cognitive behavioral therapy methods (Chalfant et al. 2007; Wood et al. 2009). However, there is little known about how these interventions or treatment strategies are used in routine care and the nature of CMH services more generally. Detailed research on usual care service contexts and treatment for childhood disorders is critical to bridge the gap between what is known about research-based and community-based practices (Bickman 2000; Hoagwood and Kolko 2009; McLennan et al. 2008; Westfall et al. 2007).

The current study primarily focuses on care provided in outpatient CMH clinics that serve a broad range of childhood disorders (i.e. do not specialize in any specific disorders). Although providers in these clinics do not typically specialize in serving children with ASD, research indicates that a vast majority of therapists have served a child with ASD in this setting and children with or suspected of having ASD represent, on average, 21% of therapists’ caseloads (Brookman-Frazee et al. 2011). Previous studies using administrative datasets indicate that children with ASD receive outpatient psychotherapy for similar problems as children without ASD (e.g., disruptive behaviors) within the same system (Mandell et al. 2005).

Based on what is known about usual care provided in CMH clinics, care may not be as effective as treatment provided in controlled research settings. Many CMH clinics were not designed to serve children with developmental disabilities and it is likely that CMH therapists providing treatment to children with ASD lack specialized training in this spectrum of disorders. Research on community providers’ knowledge about ASD indicates that providers (including mental health professionals) hold a number of inaccurate beliefs about ASD (Heidergerken et al. 2005). Therapists have limited training in ASD and are highly frustrated serving this population (Brookman-Frazee et al. 2011). Moreover, observational data of outpatient therapy provided in CMH clinics suggest that therapists use similar strategies with school-age children with and without ASD and indicate discrepancies between evidence-based practices (EBPs) and usual care (Brookman-Frazee et al. 2010). This finding is consistent with research on usual care psychotherapy for children with disruptive behavior problems more broadly (Garland et al. 2010), and early intervention/ education services for children with ASD (Stahmer 2007; Stahmer et al. 2005). Improvement in care provided in CMH clinics to children with ASD is clearly warranted.

Improving the quality of CMH care requires comprehensive approaches that include the integration of EBPs. An important component of efforts to implement EBPs is gathering information about the community context and needs (Chorpita et al. 2002). This includes gathering the perspectives of relevant community stakeholders on their needs and preferences (e.g., Brownson et al. 2009). It also includes information on the clinical characteristics of the children served in the community context. Our previous research has examined therapist perspectives on serving children with ASD in CMH clinics (Brookman-Frazee et al. 2011). As mentioned previously, results indicate that most therapists practicing in CMH clinics have served children with ASD and few have specialized ASD training. Therapists primarily serve children with Asperger's Disorder and PDD-NOS referred for behavior problems and other co-occurring psychiatric problems. Understanding parent perspectives on their children and community-based services also has important implications for improving care for children with ASD because parents are involved in initiating and continuing treatment for this population, and parent groups have been particularly influential in driving ASD research, treatment funding and policy (Singh et al. 2009), and parents are considered key stakeholder's in children's mental health services (Hoagwood 2005; Huang et al. 2005).

Despite growing data on parent perspectives of community care, generally, for children with ASD (Dymond et al. 2007; Kohler 1999; Montes et al. 2009), no study to date has thoroughly examined parent perspectives regarding the CMH service system specifically. Detailed information on parents' perspectives of CMH services, particularly related to access, utilization and effectiveness is important to design relevant programming to increase access to services and improve the implementation of evidence-based interventions in these settings. Further, little is known about the clinical histories of children with ASD served in CMH clinics. This study was designed to gather in-depth information about the CMH system from parents' standpoint and examine specific factors related to access and perceived treatment effectiveness as part of a larger study aimed to improve CMH services for children with ASD. The current study specifically examines parent perspectives on: (1) clinical histories of children with ASD involved in CMH clinics, (2) their experiences accessing these services including pathways into services, barriers to care and service utilization histories, and (3) the impact of CMH clinic services on child and parent functioning.

Methods

Design

The current qualitative study examining parent perspectives was conducted as part of a larger mixed-methods research program aimed to gather information about the clinical needs of children and their families, and the training needs of CMH providers to develop targeted improvement efforts. Specifically, this information was sought to develop and test an intervention protocol and corresponding therapist training model that integrates evidence-based intervention strategies in CMH clinics.

Qualitative methods were used because of the exploratory nature of the aims and because they are particularly well-suited for gathering in-depth information about parents' subjective experiences about care for their children (Marshall and Rossman 2006). The focus was purposely broad in nature to elicit meaningful themes, gathering in-depth information to fully grasp the complexities of CMH care for this unique population.

Participants

Twenty-one semi-structured interviews were conducted with 23 parents (two parents were present for two of the 21 interviews) of children with an ASD who had received (or were currently receiving) outpatient therapy in CMH clinics. One parent had two children with ASD and described her experiences with both children. Parents were recruited through fliers posted in CMH clinics and on local ASD websites and through parent support groups. Participants ranged in age from 29 to 78 years, were 83% female and 78% Caucasian, 9% Multi-racial, 4% African American, 4% Hispanic/Latino, and 4% Asian American. Their children ranged in age from 6 to 19 years, were 59% male and 64% Caucasian, 23% Multi-racial, 9% Asian American/Pacific Islander, and 5% African American. Characteristics of individual parent participants are reported in Table 1.

Procedures

Informed consent was obtained from all participants. Interviews were approximately 90 minute in length and were conducted either at the families' homes or in an office at our research center. Parents received a small compensation for their time. The study procedures were approved by the relevant Institutional Review Boards. A semi-structured, interview structure was used to obtain information on child clinical histories (e.g., diagnostic history, psychiatric co-morbidity), service use history, pathways to mental health services, barriers to accessing effective mental health services, and perceptions of the impact of mental health services. The questions were open-ended so that interviewees could elaborate on their experiences. They were presented in a broad to specific sequence.

Data Analysis

Data were analyzed using a coding, consensus, and comparison methodology (Willms et al. 1990) which followed an iterative approach rooted in grounded theory (Glaser and Strauss 1967). First, audiotapes of all interviews were transcribed. Several transcriptions were then independently coded by the research team at a very general level in order to condense the data into analyzable units. Transcript segments ranging from a phrase to a paragraph were assigned codes based on emergent themes (i.e., themes that arose from the interview data). Disagreements in assignment or description of codes were resolved through discussion and enhanced definition of codes. The final list of codes, constructed through a consensus of research team members, consisted of a list of themes, issues, and attitudes that related to parents perspectives on CMH services.

Five research team members coded the transcripts. For the two instances in which two parents were present, both caregivers' responses were transcribed and coded. For the interview in which the parent described her experiences with two children with ASD, responses about each specific child were coded separately. General comments about service navigation or service system were only coded once. The transcripts were then assessed for coding agreement among the research team. The codes were categorized into two levels: general (codes at the broadest level of themes), and subthemes (codes at the second level of themes). Transcripts were then entered, coded, and analyzed in QSR-NVivo 2.0, a software package that is widely used to support qualitative research (Tappe 2002). This program was used to facilitate the process of axial coding by organizing data within a tree-like structure of nodes/categories. Finally, using a process of constant comparison (Glaser and Strauss 1967), taxonomies of codes were created for the interviews and compared with one another to identify themes and subthemes related to parent perspectives on mental health services for children with ASD.

Results

Responses are reported in the categories identified in the initial aims of the study. These include child clinical characteristics and clinical histories, service access and experiences with mental health services. Each category represented a specific stage in an illness trajectory (Garro 1992) beginning with illness genesis, realization of illness disruption on life, search for a diagnosis, and experience with treatment. Participant verbatim quotes are presented to illustrate examples of important themes. Two to four themes were identified related to each category. Themes are summarized in Table 2.

Child Characteristics and Clinical Histories

Overall, parents described their children as clinically complex as reflected by the children's clinical profile, diagnostic history and process, co-occurring problems, and impact of ASD on family. These characteristics are described below.

Clinical Profile—Almost all parents reported that their children had high functioning (Asperger's Disorder) or non-specific ASD diagnoses (PDD-NOS; i.e., few had "classic" autism). Few parents reported intellectual disability which was supported by few children qualifying for MR/DD services. All parents reported that their children had difficulty in communication, social interaction, and restrictive and repetitive behaviors and interests, suggesting that their symptoms were consistent with an ASD diagnosis.

Diagnostic History and Process—Most parents reported a pathway to ASD diagnosis as follows: (1) early concerns, (2) reassurance or concerning behaviors attributed to other problems by professionals (e.g., physicians, educators, therapists), (3) multiple professionals involved with multiple and conflicting diagnoses provided, and (4) an ASD diagnosis provided after age five that finally "fit" the child. Although almost all of the children were diagnosed with an ASD after the age of five, parents reported being concerned at very early ages (<18 months). Many parents reported that, in response to their concerns, they were reassured about their children's development.

> We noticed early on a number of her difficulties –difficulties crawling, no inability to turn over, inability to hold her head up. When we tried to raise this with the doctors, we were basically told that these children essentially grow out of these things and it's just the delays and the attention and nurturing will make a difference. At times, we were made to feel as if we had these exaggerated expectations…

Other parents reported that their children's problems were attributed to poor parenting or adjustment problems.

> Kindergarten was a nightmare…he spent a lot of time crying. And parents that I didn't know… [would] come up and tell me to take him out of school… I took him to a therapist. They called it adjustment reaction to my divorce, but I knew it was something more to it because – there were just odd things about him.

In almost all cases the diagnostic process was lengthy, multiple professionals (e.g., pediatricians, neurologists, psychiatrists, psychologists) were involved, and the child received a number of other diagnoses prior to being diagnosed with an ASD.

> He talked to her for like ten minutes and … said, 'Okay, here's the deal. She's… anxious, depressed, ODD, and OCD, and we need to put her on these five medications.'

A few parents indicated that a professional mentioned early onset schizophrenia prior to an ASD diagnosis. After receiving a diagnosis of an ASD, many parents reported that they felt that the ASD diagnosis was the first to accurately capture the child's symptoms.

> He was diagnosed in the third grade with Asperger's and… it really explained a lot of the challenges that we had been facing since he started school.

Overall, parents consistently indicated that the diagnostic process was confusing and highly stressful, although many also indicated that they were relieved once their children were diagnosed with an ASD.

Co-Occurring Problems—Most parents reported co-occurring psychiatric problems and all parents reported significant behavior problems that were the primary reason for receiving CMH services. Many also had co-occurring medical problems such as seizure disorders. The most frequently mentioned psychiatric problems were ADHD, anxiety disorders, and mood disorders.

> Well, the… OCD… that was what sort of led to Luvox…[Child] hates germs and everything else, and occasionally he's done too much hand washing. But at this stage, when he was out of control…all up his arms, it was just all red raw from him continually hand washing.

Parents also reported that their children exhibited significant challenging behaviors and indicated that the impact of the child's behavior caused significant stress. Many parents described their children as aggressive and indicated that their children's behaviors resulted in being expelled from multiple school placements.

Positive and Negative Impacts of Child Characteristics on Family—Parents reported both positive and negative impacts of having a child with ASD. Multiple parents reported that it was "fun" to have a child with autism and shared their appreciation of their children's unique perspective.

> I don't wish… for her to be any other way than she is… I think my daughter is just so cool. And, it's actually really fun [laughs] to have a kid with autism… I think the way her mind works and a way a lot of the kids' minds work … is wonderful and… to be so free and so honest that it's just, it's almost admiring. You know, you wish you could be that free and that honest…

Parents also readily described their children's strengths including intelligence, high energy and sense of humor. Further, while some parents reported feeling embarrassed by their children's behaviors, others described positive responses.

> I used to be concerned about what other people thought and how they felt, and, like going to the mall with her, going to the grocery store. And then I got to that point, 'You know what? I really don't care.' You know, if she decides that she wants to dance in the middle of the mall, you know, it's like, 'Okay, let's dance.'

As above, many parents reported considerable stress related to their children's symptoms, particularly the challenging behaviors, and the diagnostic process. Further, they indicated that children's behavior resulted in disruptions in daily life. This stress appeared particularly high for single parents.

> I was a single mom. I've no family here and I was struggling financially so I was losing a lot of time from work …I just couldn't seem to get help for him. He would get kicked out of school, he would get kicked out of his daycare center, then I got to the point where he couldn't go to school or to daycare so I had to stay home from work with him and then even the neighbors would come over and tell me not to let him outside.

Other parents described anger or resentment over their children's behavior.

Service Access

There were a number of themes under this category. Specifically, child, organizational and service system characteristics emerged related to accessing services. Pathways to CMH services included child behavior problems triggering a referral to mental health services and the central role of the education system, while service system issues were perceived as barriers to access. Further, parents described accessing services, generally, as a highly stressful process.

Child Characteristics (Behavior Problems)—Severe behavioral escalations or significant behavior problems in the school setting frequently triggered access to CMH services. For many families, referral to CMH services occurred prior to receiving an ASD diagnosis. Due to significant problem behaviors occurring at school, school staff often recommended that families seek an evaluation for mental health services.

> …she was giving boys black eyes because they were picking on her friend…so… three, four, sometimes more a month, we were having these behavioral meetings… then her teacher's like,… 'I'm not telling you this, but you should ask for mental health services.' So I asked for it…and they did…the evaluation with her and then they went to school to see how she acted. And then I got a call from [school district], saying that [Child] was eligible through AB2726 [described below].

Other times, the parent became well aware of the risk the child posed for harming others which led them to seek a mental health evaluation.

> I know at school, they were concerned that his behavior was getting so out of control…and that was another reason why I finally… had to break down and I had to go and do something I didn't want to do. Because they were concerned that he was going to hurt somebody or would get to a point where they would have to call in the authorities and at that stage, it will be taken out of my hands. So, I know that was a concern, but luckily we were able to get him help quickly enough so that it circumvented that.

A few parents also mentioned behavior problems outside of the school setting prompting the referral to mental health services.

System Factors: Central Role of Education System—For all respondents, the education system played an important role in facilitating access to CMH services. It was the primary referral and funding source for CMH services. The referral to CMH services was typically facilitated through funding allocated through the California Assembly Bill AB2726/3632 which provides state funding for students in California whose mental health problems are deemed to interfere with academic functioning. Interestingly, most parents did not distinguish between the CMH and education systems. This was evident as they also responded to questions about CMH services by describing education services or viewed CMH services as an extension of education services.

System Factors: Service Navigation Issues—Parents reported frustration with their lack of understanding about the service system and which services to use at each point in their children's development. They described how their eligibility for services changed over time which consequently forced their children to move from one type of service to another with little information shared from one service agency to another. Parents also reported that their children often did not qualify for a specific set of services funded through the developmental disability service sector due to the child's high functioning ASD diagnosis even though they felt that the child was in need of those types of services.

> …And our experience was that, once again, as if these institutions were set up to largely to disqualify a child from any kind of help and attention… so the Regional Center was extremely frustrating to us. We didn't know what to do…But of course, as soon as she turned three years old, she was disqualified yet again because they told us that now the school district would take over all over her needs and—we didn't even know all of her needs. We had no idea how to approach this.

Other parents explicitly stated that CMH services were the only services available to the child.

> …it has been suggested several times to me by different therapists that weekly outpatient therapy really isn't the thing for a child with autism. And I do have a tendency to agree with that at times, but this is all he has right now. I wish there was something more specific for children like him.

Stress Related to Accessing Services—Parents indicated that accessing appropriate services for their children was particularly stressful and daunting.

> We just, we were at a loss—we just struggled so miserably for so many years. So that was our experience… Psychologically awful…The strain was colossal, especially in the fighting over moving her to another school. We could not understand why the school couldn't recognize the importance of her needs and either provide what she needed in the school or… change the venue…it was utterly demoralizing. We were depressed and upset, and my wife would weep regularly.

Many parents indicated that accessing services for their children negatively impacted family functioning. For example, many communicated significant marital discord, feelings of guilt related to not having enough time for other children, and feelings of isolation.

Related to the significant effort required to access services, a number of parents indicated that they found interactions with professionals in ongoing services particularly stressful.

> You always have to be kind of on the defensive because sometimes people…you don't feel like they take you seriously, like you're just another case, another kid, another…it's so urgent to you, and it's just their job from nine to five and, it might go for weeks without being taken care of. So it's hard, it's a hard process.

Lastly, parents also indicated that the time and effort required to access services for their children resulted in significant financial strain to the family, particularly for single parents.

> I had a lot of…financial worries which were tearing me away and working late at night to make up for the hours I was missing because of [Child]…All my energy was focused in so many places but I was fighting for all these other services for him.

Experiences with CMH Services

Outpatient therapy and medication management were the most frequently reported types of CMH services utilized. Although some parents indicated that these services were helpful in reducing behavior problems, increasing social skills, providing emotional support to the child or teaching strategies to the parents, many parents indicated that their children made minimal progress.

> How much [Child] actually benefits is questionable… I see that some of the people are really just trying to figure out information and really just don't know what to do to help.

Other parents reported concern with the rate of the child's progress. Commonly reported challenges to effective services included lack of provider training and specialized ASD services, organizational factors, and lack of coordination across service providers.

Lack of Clinician ASD Training and Specialized ASD Services—The most frequently reported challenge to effective CMH services was the perceived lack of provider knowledge about treating children with ASD. This included both PhD and MA-level therapists and psychiatrists providing medication management.

> I would be concerned that some of them are with providers that maybe aren't as well suited to, to work with them if they don't have the background and the understanding of…the condition and what kind of supports those kids need. 'Cause I think they are different from a lot of other types of mental health needs.

Some parents reported that the providers themselves acknowledged that they were not skilled in working with this population and would refer them elsewhere. Parents also stated that they felt providers, therapists specifically, needed more training specific to ASD issues and in using parent training models so that the parents could learn and use the effective strategies as well. The few parents who did indicate that their children made progress reported that the CMH providers had specialized ASD training.

Organizational Factors—Many parents mentioned organizational factors such as high clinic staff turnover, especially among trainees, impacting the consistency and effectiveness of care, particularly therapy.

> The other difficulty with going with County Mental Health is their turnover…That was really hard. Especially [if] there was one there that was really good…we had one that was like three months and then another one… And I'm like, you know, this is really too hard for him…so that was the hardest part.

Other parents noted that changes in staff are particularly challenging for children with ASD who have a difficult time with transitions, change and building positive trusting relationships with others.

> …every summer, he knows he gets a new teacher, and a new therapist, and while he was on meds, a new psychiatrist. So that's three new people to get to know and feel comfortable with. [That's] just real hard for kids with autism…so having someone that he could see continuously…that would be, probably the one biggest thing.

Discussion

This study examined parent perspectives about CMH services for their children with ASD. Parents provided information about the characteristics of their children, their experiences receiving an ASD diagnosis, access to CMH services, and experiences with CMH services. These categories represented specific stages in an illness trajectory (e.g., illness genesis, realization of illness disruption on life, search for a diagnosis and effective treatment; Garro 1992). There were common pathways to diagnosis and CMH services and general dissatisfaction with the process of accessing and receiving CMH services. Each stage of this trajectory was marked by high parent stress as evidenced from both the content of parents' responses and the strong negative emotion with which parents described their experiences.

The high levels of stress related to child characteristics and behaviors described by families in this study is consistent with the existing literature on stress in families of children with ASD (Boyd 2002; Dunn et al. 2001; Tomanik et al. 2004). The findings of this study extend the literature in this area by highlighting the significant stress and negative impact manifested in psychological and financial strain, and family disruption related to accessing services.

Parents described many common child characteristics and clinical histories. Specifically, children in this study shared a clinical profile of high functioning or non-specific ASD diagnoses, a lengthy and complicated diagnostic history, and co-occurring psychiatric and behavior problems. The diagnostic profile and co-occurring problems observed in the current study are consistent with a quantitative study (Brookman-Frazee et al. 2010) and a mixed methods study conducted with therapists providing care in CMH clinics (Brookman-Frazee et al. 2011). Research also suggests that children with early psychiatric or neurological problems are likely to be diagnosed with an ASD later than those without co-occurring problems, suggesting that other symptoms or disorders may be masking core symptoms of ASD (Levy et al. 2010).

The results from this study regarding parents' frustration and stress with the complicated, lengthy diagnostic process are consistent with previous research examining parents' experiences with the diagnostic process in general. Osborne and Reed (2008), for example, reported that the diagnostic process was chaotic and emotionally unsupportive for families and the fewer providers parents had to interact with and the faster the process, the less stress parents experienced. The current study adds to the literature by highlighting the role of psychiatric symptoms further complicating the diagnostic process.

Child, organizational and service system characteristics were related to accessing services. Behavioral escalation at school frequently prompted referral to CMH services (provided primarily in outpatient clinics) and the education system also typically funded these services. As such, many parents did not distinguish between the education and CMH systems. Parents reported that service navigation issues served as barriers to access CMH (and other) services. For example, parents indicated that they did not understand the service system and were unsure of what types of services to use at specific times in their child's development. Further, due to the nature of the child's clinical profile, parents often struggled to obtain services due to ineligibility. Most parents reported that their children did not qualify for MR/DD services, which resulted in the CMH system being the "default" system for non-education services. Clear guidelines on coordination of care between CMH and education providers and distinction between the roles of each would be useful for both parents and providers as these are the two primary service systems for the subgroup of children with ASD receiving care in mental health settings.

Related to experiences with CMH services, parents most often reported that their children received medication management and/or outpatient therapy. Although they expected improved child behavior and social skills through CMH services, overall, parents felt that children made minimal progress. Parents reported a number of barriers to receiving effective CMH services for their children. The primary barrier to effective CMH services was providers' lack of specialized ASD knowledge and training. Organizational factors (e.g., the high staff turnover rate) were also considered to negatively impact care. Parents' perceptions that providers do not tailor treatment to the needs of children with ASD is very consistent with observational research showing that therapists working in CMH clinics deliver very similar treatment strategies to children with and without ASD (Brookman-Frazee et al. 2010). It is important to note that a small group of parents described a reduction in stress related to their child's behavior and service navigation once their children received services from a provider specializing in ASD.

Overall, the results of this study are consistent with the qualitative research that has examined parents' perspectives of ASD-related services in general and noted shortcomings in the access of information about and availability of appropriate ASD services, providers' ASD knowledge, and collaboration between parents and professionals (Carbone et al. 2010; Dymond et al. 2007; Kohler 1999; Renty and Roeyers 2005; Sperry et al. 1999).

Implications

Parents in the present study viewed services provided in CMH clinics as one of the few service options available due to their children's clinical profile and resulting ineligibility for more specialized ASD services. Parents consistently voiced their frustration and disappointment with the process of accessing and receiving community services and very clearly articulated the barriers they encountered in receiving effective mental health care. This underscores the importance of improving CMH services for these families. Parents consistently discussed the need to train CMH providers, especially therapists, to work with children with ASD to improve child behavior and coordination of services, particularly between the Education and CMH systems, for their child.

In most cases, both families and professionals had identified problems with the child at young ages and many children received mental health services prior to receiving an ASD diagnosis. This highlights the potential role of the CMH system in identifying ASD. It often took many years for an ASD diagnosis to be assigned. In particular, better identification for high functioning children with co-occurring problems is clearly warranted within the CMH system. In the past few decades, there have been significant movements to educate pediatricians and even school professionals on recognizing the signs of ASD in young children. Similar efforts may be warranted for CMH providers to facilitate earlier recognition of ASD in children with complex profiles.

In addition to training providers to identify ASD within the CMH population, providers clearly require training in providing intervention for children with ASD. This is particularly important for those providing psychosocial interventions. Parents indicated that the primary reason for referral to CMH services, regardless of their children's ASD and co-morbid psychiatric diagnoses, was to reduce behavior problems such as aggression. Therefore, training providers to address behavior problems would be an important starting point for training. Additionally, many parents also voiced support for increased parent involvement in treatment (e.g., learning strategies from the therapist to manage child behavior). Evidence-based treatments for behavior problems in ASD often include parent training interventions and have the added benefit of reducing parent stress (Koegel et al. 1996; Moes 1995). Preliminary support exists for the effectiveness of parent training methods in community-based settings (Baker-Ericzén et al. 2007; Stahmer and Gist 2001). Likewise, there is also clearly a need to provide training to CMH providers on how to better coordinate services between the Education and CMH systems given that they are often linked (e.g., through funding mechanisms), but not necessarily coordinated.

Limitations

A few limitations should be noted. First, the generalizability of the current study's conclusions may be impacted by the self-selection recruitment process that occurred (parents responded to an invitation to participate in the interview), relatively small and homogeneous sample. These parents may have been motivated to participate due to their stronger feelings regarding their experiences with CMH providers relative to parents who chose not to participate. Second, since the current study was conducted with a small number of parents in Southern California, it is not clear if results can be generalized to areas outside of this study location. However, research that has been conducted in other parts of the U.S and internationally has reported similar findings regarding the dissatisfaction of parents with services available for children with ASD and the need for improved services particularly via more specialized ASD provider training (Bilgin and Kucuk 2010; Montes et al. 2009; Osborne and Reed 2008; Renty and Roeyers 2005). Third, no formal assessment was conducted to confirm the parent-reported ASD diagnosis of the children.

Input from community stakeholders, including parents and providers, can increase the potential effectiveness of interventions implemented in community settings. This study was conducted as part of a comprehensive line of research aimed to tailor the implementation of EBPs in CMH clinics to the clinical needs of children with ASD served in these settings and the training needs of the providers who serve them.

Information gathered through this study was combined with findings from an observational study of usual care psychotherapy (Brookman-Frazee et al. 2010), mixed method study on provider perspectives of CMH services for ASD (Brookman-Frazee et al. 2011), and the literature on EBPs for children with ASD (National Autism Center 2009) to develop a mental health intervention protocol for children with ASD served in CMH clinics and corresponding therapist training model. The resulting intervention protocol (*An Individualized Mental Health Intervention for Children with ASD; AIM HI*) is a package of parent-mediated and child-focused EBP strategies, based on the principles of applied behavior analysis, designed to reduce behavior problems in children with ASD ages 5–13 served in CMH clinics (Brookman-Frazee and Drahota 2010). Results of a recent pilot study indicate that CMH therapists working in CMH clinics participate in ongoing ASD training, are able to deliver the intervention with fidelity, and perceive the intervention as useful. Meaningful reductions in child problem behaviors occurred over 5 months providing promising support for the intervention. This line of research highlights the utility of incorporating community stakeholder perspectives from the outset to ensure the “fit” of interventions in community settings.

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References

Baker-Ericzén MJ, Stahmer AC, Burns A. Child demographics associated with outcomes in a community-based pivotal response training program. Journal of Positive Behavior Interventions. 2007; 9(1):52–60.

Bickman L. The most dangerous and difficult question in mental health services research. Mental Health Services Research. 2000; 2(2):71–72.

Bilgin H, Kucuk L. Raising an autistic child: Perspectives from Turkish mothers. Journal of Child and Adolescent Psychiatric Nursing. 2010; 23(2):92–99. [PubMed: 20500625]

Boyd BA. Examining the relationship between stress and lack of social support in mothers of children with autism. Focus on Autism and Other Developmental Disabilities. 2002; 17(4):208–215.

Brookman-Frazee, L.; Drahota, A. An individualized mental health intervention for children with autism spectrum disorders: A model to address challenging behaviors in children with ASD (unpublished manual). San Diego: University of California; 2010.

Brookman-Frazee, L.; Drahota, A.; Stadnick, N.; Palinkas, LA. Administration and Policy in Mental Health and Mental Health Services Research. 2011. Therapist perspectives on community mental health services for children with autism spectrum disorders.

Brookman-Frazee LI, Taylor R, Garland AF. Characterizing community-based mental health services for children with autism spectrum disorders and disruptive behavior problems. Journal of Autism and Developmental Disorders. 2010; 40(10):1188–1201. [PubMed: 20204690]

Brownson RC, Fielding JE, Maylahn CM. Evidence-based public health: A fundamental concept for public health practice. Annual Review of Public Health. 2009; 30:175–201.

Carbone PS, Behl DD, Azor V, Murphy NA. The medical home for children with autism spectrum disorders: Parent and pediatrician perspectives. Journal of Autism and Developmental Disorders. 2010; 40(3):317–324. [PubMed: 19768528]

Chalfant AM, Rapee R, Carroll L. Treating anxiety disorders in children with high functioning autism spectrum disorders: A controlled trial. Journal of Autism and Developmental Disorders. 2007; 37(10):1842–1857. [PubMed: 17171539]

Chorpita BF, Yim LM, Donkervoet JC, Arensdorf A, Amundsen MJ, McGee C, et al. Toward large-scale implementation of empirically supported treatments for children: A review and observations by the Hawaii Empirical Basis to Services Task Force. Clinical Psychology: Science and Practice. 2002; 9(2):165–190.

Dunn M, Burbine T, Bowers C, Tantleff-Dunn S. Moderators of stress in parents of children with autism. Community Mental Health Journal. 2001; 37(1):39–51. [PubMed: 11300666]

Dymond SK, Gilson CL, Myran SP. Services for children with autism spectrum disorders. Journal of Disability Policy Studies. 2007; 18:133–147.

Garland AF, Brookman-Frazee L, Hurlburt MS, Accurso EC, Zoffness RJ, Haine-Schlagel R, et al. Mental health care for children with disruptive behavior problems: A view inside therapists' offices. Psychiatric Services. 2010; 61(8):788–795. [PubMed: 20675837]

Garro, L. Chronic illness and the construction of narratives. In: Good, MJ.; Brodwin, PE.; Good, BJ.; Kleinman, A., editors. Pain as human experience: An anthropological perspective. Berkeley: University of California Press; 1992. p. 100-137.

Glaser, B.; Strauss, A. The discovery of grounded theory. Chicago: Aldine; 1967.

Heidergerken AD, Geffken F, Modi A, Frakey L. A survey of autism knowledge in a health care setting. Journal of Autism and Developmental Disorders. 2005; 35(3):323–330. [PubMed: 16119473]

Hoagwood KE. Family-based services in children's mental health: A research review and synthesis. Journal of Child Psychology and Psychiatry. 2005; 46(7):670–713.

Hoagwood K, Kolko DJ. Introduction to the special section on practice contexts: A glimpse into the nether world of public mental health services for children and families. Administration and Policy In Mental Health. 2009; 36(1):35–36. [PubMed: 19115103]

Huang L, Stroul B, Friedman R, Mrazek P, Friesen B, Pires S, et al. Transforming mental health care for children and their families. American Psychologist. 2005; 60:615–627. [PubMed: 16173894]

Koegel RL, Bimbela A, Schreibman L. Collateral effects of parent training on family interactions. Journal of Autism and Developmental Disorders. 1996; 22:141–152. [PubMed: 1378049]

Kohler F. Examining the services received by young children with autism and their families: A survey of parent response. Focus on Autism and Other Developmental Disabilities. 1999; 14:150–158.

Lainhart J. Psychiatric problems in individuals with autism, their parents and siblings. International Review of Psychiatry. 1999; 11(4):278–298.

Levy SE, Giarelli E, Lee L, Schieve L, Kirby RS, Cunniff C, et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. Journal of Developmental and Behavioral Pediatrics. 2010; 31(4):267–275. [PubMed: 20431403]

Leyfer OT, Folstein SE, Bacalman S, Davis NO, Dinh E, Morgan J, et al. Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. Journal of Autism and Developmental Disorders. 2006; 36(7):849–861. [PubMed: 16845581]

Mandell DS, Walrath CM, Manteuffel B, Sgro G, Pinto-Martin J. Characteristics of children with autistic spectrum disorders served in comprehensive community-based mental health settings. Journal of Autism and Developmental Disorders. 2005; 35(3):313–321. [PubMed: 16119472]

Marshall, C.; Rossman, GB. Designing qualitative research. 4. Thousand Oaks: Sage Publications; 2006.

McLennan JD, Huculak S, Sheehan D. Brief report: Pilot investigation of service receipt by young children with autistic spectrum disorders. Journal of Autism and Developmental Disorders. 2008; 38(6):1192–1196. [PubMed: 18324468]

Moes, D. Parent education and parenting stress. In: Koegel, RL.; Koegel, LK., editors. Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities. Baltimore: Paul H. Brookes Publishing Co; 1995.

Montes G, Halterman JS, Magyar CI. Access to and satisfaction with school and community health services for children with autism: National overview. Pediatrics. 2009; 124:S407–S413. [PubMed: 19948606]

National Autism Center. National standards project—Addressing the need for evidence-based practice guidelines for autism spectrum disorders. 2009. from http://www.nationalautismcenter.org/about/national.php

National Research Council. Educating children with autism. Washington, DC: National Academy Press, Division of Behavioral and Social Sciences and Education, Committee on Educational Interventions for Children with Autism; 2001.

Osborne LA, Reed P. Caregivers' perceptions of communication with professionals during the diagnosis of autism. Autism. 2008; 12:259–274.

Renty J, Roeyers H. Satisfaction with formal support and education for children with autism spectrum disorder: The voices of the parents. Child: Care, Health and Development. 2005; 32(3):371–385.

Simonoff E, Pickles A, Charman T, Chandler S, Loucas T, Baird G. Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. Journal of the American Academy of Child and Adolescent Psychiatry. 2008; 47(8):921–929. [PubMed: 18645422]

Singh J, Illes J, Lazzeroni L, Hallmayer J. Trends in US autism research funding. Journal of Autism and Developmental Disorders. 2009; 39(5):788–795. [PubMed: 19148735]

Sperry LA, Whaley KT, Shaw E, Brame K. Services for young children with autism spectrum disorders: Voices of parents and providers. Infants and Young Children. 1999; 11(4):17–33.

Stahmer AC. The basic structure of community early intervention programs for children with autism: Provider descriptions. Journal of Autism and Developmental Disorders. 2007; 37(7):1344–1354. [PubMed: 17086438]

Stahmer AC, Collings NM, Palinkas LA. Early intervention practices for children with autism: Descriptions from community providers. Focus on Autism and Other Developmental Disabilites. 2005; 20(2):66–79.

Stahmer AC, Gist K. The effects of an accelerated parent education program on technique mastery and child outcome. Journal of Positive Behavior Interventions. 2001; 3(2):75–82.

Tappe, A. Using NVivo in qualitative research. Melbourne: QSR International; 2002.

Tomanik S, Harris GE, Hawkins J. The relationship between behaviours exhibited by children with autism and maternal stress. Journal of Intellectual and Developmental Disability. 2004; 29(1):16–26.

Westfall JM, Mold J, Fagnan L. Practice-based research—"Blue Highways" on the NIH roadmap. Journal of the American Medical Association. 2007; 297(4):403–406. [PubMed: 17244837]

Willms DG, Best AJ, Taylor DW, Gilbert JR, Wilson DMC, Lindsay EA, et al. A systematic approach for using qualitative methods in primary prevention research. Medical Anthropology Quarterly. 1990; 4:391–409.

Wood JJ, Drahota A, Sze K, Har K, Chiu A, Langer DA. Cognitive behavioral therapy for anxiety in children with autism spectrum disorders: A randomized, controlled trial. Journal of Child Psychology and Psychiatry. 2009; 50:244–254.

Table 1

Participant characteristics

Participant	Gender	Age	Race/ethnicity	Marital status	Relationship to child	Highest level of education	Child’s age
1a & b	Male	78	Caucasian	Married	Adoptive	High School	14
	Female	74	Caucasian	Married	Adoptive	High School	
2a & b	Male	46	Caucasian	Married	Bio	Bachelor’s	13
	Female	43	Hispanic	Married	Bio	Bachelor’s	
3	Female	42	Caucasian	Married	Bio	High School	10 & 13
4	Female	29	Caucasian	Single	Bio	High School	9
5	Female	42	Caucasian	Single	Bio	High School	8
6	Female	29	African American	Married	Bio	Associate’s	10
7	Male	52	Asian American	Married	Bio	High School	13
8	Female	39	Caucasian	Single	Bio	High School	12
9	Female	44	Multi-racial	Single	Bio	High School	7
10	Female	47	Caucasian	Single	Bio	Associate’s	15
11	Female	52	Caucasian	Married	Adoptive	Bachelor’s	15
12	Female	35	Caucasian	Married	Bio	Bachelor’s	6
13	Female	48	Multi-racial	Married	Bio	Bachelor’s	14
14	Female	45	Caucasian	Married	Bio	Master’s	13
15	Female	36	Caucasian	Single	Bio	Master’s	16
16	Female	44	Caucasian	Married	Bio	Master’s	10
17	Female	35	Caucasian	Single	Bio	Bachelor’s	14
18	Female	45	Caucasian	Single	Bio	Bachelor’s	19
19	Male	61	Caucasian	Married	Adoptive	Doctorate	12
20	Female	41	Caucasian	Married	Bio	High school	14
21	Female	46	Caucasian	Married	Bio	Doctorate	11

Table 2

Summary of key themes

Category/subcategory	Theme
Child clinical characteristics and clinical histories	
Clinical profile	High functioning or non-specific ASD diagnoses (i.e., Asperger's Disorder, PDD-NOS)
	Few with intellectual disability or who qualify for MR/DD services
	Symptoms consistent with ASD (communication & social interaction problems; repetitive behaviors and interests)
Diagnostic history and process	Pathway:
	Early concerns
	Reassurance or concerning behaviors attributed to other problems by professionals (e.g., physicians, educators, therapists),
	Multiple professionals involved with multiple and conflicting diagnoses provided
	ASD diagnosis given after age five that finally “fit” the child
	Process confusing and highly stressful
Co-occurring problems	Significant behavior problems:
	Primary reason for receiving CMH services
	Source of parent stress
	Other common psychiatric problems—ADHD, anxiety disorders, and mood disorders
	Medical problems (e.g., seizure disorders)
Impact of child characteristics on family	Positive perceptions of ASD characteristics many child strengths
	Difficulties contribute to high levels of stress and disruptions in daily life
Service access	
Child characteristics	Severe behavioral escalations or significant behavior problems in the school setting frequently triggered access to CMH services
System factors	Central role of education system in facilitating access to CMH services:
	Primary referral and funding source
	Distinction between the CMH and education systems unclear
	Service navigation challenges:
	Lack of understanding about the service system
	Ineligibility for MR/DD services due to high functioning ASD diagnosis
	Accessing appropriate services stressful and daunting
	Impacts of service navigation and interactions with professionals:
	Source of stress, family disruption and financial strain
Experiences with mental health services	
Types of services	Outpatient therapy and medication management frequently utilized
Impact	Reducing behavior problems, increasing social skills, providing emotional support to the child or teaching strategies to the parents
	Minimal, slow progress
Challenges to effective services	Lack of clinician ASD training and specialized ASD services
	Organizational factors (e.g. high staff turnover)