Integration of mental health services into an innovative health care delivery model for children with chronic conditions

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ABSTRACT

Coordinated Healthcare for Complex Kids (CHECK) is an innovative health care delivery demonstration project for children with chronic conditions and is supported by the Centers for Medicare and Medicaid Services Health Care Innovation Award Round Two. CHECK integrated behavioral health care into the model of comprehensive healthcare delivery. CHECK has provided a total of 31,470 services to 5923 children and their families. CHECK has provided 12,243 mental health screenings, 18,411 preventive interventions, 7511 consultative services, 2443 direct interventions, and 3105 referral services. A significant relationship was found between type of mental health service and disease and age. Children received different types of mental health services based on their type of chronic medical condition and age. CHECK is a promising model that has the potential to inform the development of future integrated health and behavioral health care service delivery models for children and youth with chronic medical conditions.

1. Introduction

An estimated 13%–20% of children have a mental, emotional, or behavioral (MEB) disorder, and prevalence is increasing annually (Perou, Bitsko, Blumberg, et al., 2013). The problem is even worse in children with chronic medical conditions who have an estimated 25% prevalence of MEB disorders (Brown, Green, Desai, Weitzman, & Rosenthal, 2014; Inkelas, Raghavan, Larson, Kuo, & Ortega, 2007), and about 40% have clinically significant MEB problems that do not meet criteria for diagnosis of a disorder (Anthony & Booth, 2017; Bernal et al., 2000; Briggs-Gowan, Horwitz, Schwab-Stone, Leventhal, & Leaf, 2000; Costello & Shugart, 1992). Most MEB problems and disorders originate in childhood, and without early treatment can affect development and have negative consequences across the life course (Anthony & Booth, 2017; National Research Council, 2009). Children and youth with untreated MEB disorders and problems often have serious difficulties at home, in school, and with peer relationships (National Research Council, 2009). They frequently engage in high-risk behavior (e.g., criminal behavior and substance abuse) and have higher morbidity and mortality rates in adulthood (National Research Council, 2009; Perou et al., 2013).

In the United States, an estimated $247 billion is spent each year for the treatment of MEB disorders and problems (Centers for Disease Control and Prevention, 2018; National Research Council, 2009). Despite the large expenditure on treatment, as many as 75–80% of children in need of mental health services never receive the services they need (Ganz & Tendulkar, 2006; Ghandour, Grason, Schempf, et al., 2013; Kataoka, Zhang, & Wells, 2002). The need is particularly high among children with chronic conditions, of whom an estimated 25% have an unmet mental health need (Ganz & Tendulkar, 2006; Glassgow & Van Voorhees, 2017; Inkelas et al., 2007; Mayer, Skinner, & Slifkin, 2004). For all children, the evidence is well-documented that early intervention (prevention, early identification, and effective treatment) for MEB disorders and problems can have a powerful positive effect on children, families, and society and influence the developmental trajectories across the life course (Dubois, Herrera, & Higley, 2018; National Research Council, 2009; Substance Abuse and Mental Health Services Administration, 2003). Evidence also suggests that integrated health and behavioral health care services improve child and youth outcomes, including having a significant effect on improving mental health problems (Asarnow, Rozenman, Wiblin, & Zeltzer, 2015). However, for children with chronic medical conditions, most current
health systems are not sufficiently supported to provide integrated mental health services to address their needs (National Research Council, 2009; Substance Abuse and Mental Health Services Administration, 2003). Health systems face challenges related to service delivery feasibility, access, and costs (Bringewatt & Gershoff, 2010).

One strategy for addressing the mental health needs of children with chronic medical conditions is to provide comprehensive, well-coordinated care that integrates health and behavioral health services (Crogan & Brown, 2010). This manuscript describes a large-scale program that addresses the gap in integrated service delivery for children and Youth and has promising preliminary findings. Coordinated Healthcare for Complex Kids (CHECK) is an integrated health and behavioral health program. CHECK is an innovative health care delivery demonstration project at a university and is supported by the Centers for Medicare and Medicaid Services Health Care Innovation Award Round Two. The aims of CHECK are to: 1) reduce healthcare costs; 2) reduce school absenteeism; and 3) foster greater patient and family engagement in care management for high-risk children and young adults with chronic disease. The general CHECK theoretical model and interventions (care coordination, provider support services, legal services, technology systems, community partnerships, oral health services) are discussed elsewhere (Glassgow et al., 2017; Martin, Perry-Bell, Minier, Glassgow, & Van Voorhees, 2018; Minier et al., 2018).

Because of the integral connection between chronic medical conditions and mental health, CHECK designed a behavioral health intervention that would be available for all CHECK patients in the community where they reside. The CHECK behavioral health model aims to identify MEB problems and disorders in children with chronic medical conditions and provide low-cost mental health services that are integrated into a comprehensive health care delivery and care coordination program. The aim was to provide more cost-effective services than traditional behavioral health services by offering both high- and low-cost services employing a combination of licensed and non-licensed mental health staff.

2. Methods

2.1. Program setting

The CHECK program is located in the Department of Pediatrics at the University of Illinois Hospital & Health Sciences System (UI Health). UI Health is an urban safety net hospital and a healthcare system that encompasses a sizeable and diverse collection of providers who are from seven health sciences colleges. UI Health has 22 outpatient care clinics, 13 Federally Qualified Health Centers, primary and specialty care for patients of all ages, pediatric dental clinics, and is designated as a pediatric critical care center, provides level 3 perinatal care, and has an emergency department approved for pediatrics. UI Health primary service area (PSA) covers approximately 2 million people from the poorest communities in Chicago, Illinois. Compared to the overall city of Chicago, the UI Health PSA has a predominantly minority population, lower levels of education, and higher levels of unemployment, poverty, and violence. For example, 21 of the 24 community areas in the UI Health PSA have a minority population > 75%. In addition, 22 had a lower average median household income compared to the city of Chicago. In 2014, several community areas in the UI Health PSA had homicide rates that were three times higher than Chicago. In general, the community areas in the UI Health PSA are struggling with multiple social and economic challenges.

2.2. CHECK patients

Enrollment began on December 1, 2014 and ended September 1, 2017. CHECK patients were referred primarily from the STATE Department of Healthcare and Family Services (i.e., the state Medicaid agency) based on Medicaid claims data. CHECK also received patient referrals from Medicaid managed care organizations (MCOs), partner clinics, hospitals, and self-referrals. Patient eligibility for services included: 1) being age 25 years or younger at the time of enrollment; 2) enrollment in traditional Medicaid (fee-for-service) or one of the managed care plans; and 3) having a diagnosis of asthma, diabetes mellitus, sickle cell disease, prematurity or other chronic medical condition.

After identifying potentially eligible patients, a letter of enrollment is sent to the patient. The letter provided information about the CHECK program, including the extra services that were available, and informed patients that they will continue to see their regular primary care provider. The letter also stated patients may opt-out of the CHECK program. After two weeks, CHECK staff attempted to contact all patients by phone to verify receipt of the letter and to confirm enrollment in the CHECK program. Once verbal confirmation was obtained, the CHECK program staff conduct an initial baseline assessment to determine the patient's medical and social service needs. Enrolled patients were defined as all patients who meet the CHECK eligibility criteria and are Medicaid recipients. Engaged patients were defined as all enrolled patients who started or completed a baseline needs assessment. As of September 1, 2017, 17,573 patients had been enrolled and 5923 (34%) patients had been engaged in CHECK. An important component of the CHECK program evaluation is determining who did and did not engage in the program. We are currently conducting analyses to determine the potential differences between the two groups and will disseminate the findings when completed.

2.3. CHECK behavioral health model

We used a Behavioral Health Stepped Care Model to deliver services to all children and their families engaged in CHECK. Services were grouped into mental health screenings, preventive interventions, consultative services, direct interventions, and referrals. Services were provided to children in their homes, community, health clinics, hospital, and via technology (e.g., online psychoeducation, short message service (SMS) two-way interaction, tele-mental health, and an online repository of social service resources that are searchable location, language, and accepted insurance plans).

2.4. Mental health screenings

CHECK implemented a 3-tiered screening process to identify families in need of behavioral health services and to determine the appropriate level of service needed.

2.4.1. Tier 1 screenings

Tier 1 was used as a universal mental health screening for all engaged CHECK children and their parents. At the time of enrollment in CHECK, staff contacted all families to conduct an initial mental health screening. A total of five mental health screening questions were asked about the child and the parent. Parents of children aged 18 and younger were asked two yes/no screening questions about their child (Do you have any current concerns about your child's development? and Do you have any current concerns about your child's behavior?). Answering yes to either question was considered a positive screening. Parents were then asked to report the number of days for two questions (Thinking about your child's mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was your child's mental health not good? and During the past 30 days, for about how many days did poor physical or mental health prevent your child from doing usual activities, such as going to school, playing, or doing other activities?). A positive screening was considered five days or more to either question. Parents and children 18 years and older were asked two questions about their own mental health (In the past 30 days how many days was your mental health not good, which
includes stress, depression, problems with emotions? and During past 30 days, how many days did poor mental health prevent you from doing usual activities, such as going to work, playing with your child, or doing other activities?). A positive screening was considered five days or more to either question.

2.4.2. Tier 2 screenings

Tier 2 screenings and assessments were administered to children or their parents that screened positive on Tier 1 screening questions. The Tier 2 screenings were then administered every six months following the initial screening. For Tier 2 screenings, children were screened using the Pediatric Symptom Checklist (PSC-17) (Gardner, Murphy, Childs, et al., 1999) and parents were screened using relevant questions selected from Patient-Reported Outcomes Measurement Information System (PROMIS®) (U. S. Department of Health and Human Services, 2016) measures and the Confusion, Hubbub, and Order Scale (CHAOS) (Matheny, Wachs, Ludwig, & Phillips, 1995). Perinatal women were screened using the Edinburgh Postnatal Depression Scale (EPDS) (Cox, Holden, & Sagovsky, 1987).

2.4.3. Pediatric symptom checklist (PSC-17)

Children ages 4 to 17 years in Tier 2 were screened using the PSC-17, a brief screening questionnaire that has been validated to detect psychosocial problems in children (Gardner et al., 1999). The 17 responses are rated on a 2-point scale (0 = never to 2 = often) with a total cutoff score of 15 or more points. Subscale scores also can be calculated for internalizing, conduct, and attention problems. Sample items include “feels sad, unhappy,” “worries a lot,” and “does not listen to rules.” The checklist was completed by the parent on behalf of the child.

2.4.4. PROMIS and CHAOS measures

PROMIS measures assess patient-reported health status for physical, mental, and social well-being (http://www.healthmeasures.net/explore-measurement-systems/promis/obtain-administer-measures) (U. S. Department of Health and Human Services, 2016). Parents were asked the 4-item versions of six PROMIS instruments. These items include: anxiety (e.g., I felt fearful), depression (e.g., I felt worthless), social roles and activities (e.g., I have trouble doing all my regular leisure activities with others), emotional support (e.g., I have someone who will listen to me when I need to talk), informational support (e.g., I have someone to give me good advice about a crisis if I need it), and instrumental support (e.g., Do you have someone to run errands if you need it?). Items are scored on a 5-point scale (0 = never to 5 = always). A 6-item version of the CHAOS scale also was administered. This scale measures environmental confusion and processes in the home. (Matheny et al., 1995) A sample item is “I have a regular morning routine.” Items are scored on a 3-point scale (0 = not at all like your own home to 3 = very much like your own home). There is not a standard cutoff score for the PROMIS questions asked by the CHECK staff.

2.4.5. Edinburgh postnatal depression scale

Perinatal women were screened using the EPDS, a 10-item self-report scale to screen women for perinatal depression (Cox et al., 1987). Responses are scored 0–3 according to increased severity of the symptom with a recommended cut-off score of 9 points. Sample items include “I have felt sad or miserable” and “I’ve been anxious and worried for no good reason.”

2.4.6. Tier 3 screenings

Tier 3 screenings were administered to all children and/or parents that had positive Tier 2 screenings. The Tier 3 screenings were then administered every 6 months following the initial screening. For the Tier 3 screenings, children aged 11–17 were screened with the Patient Health Questionnaire for Adolescents (PHQ-A) and adults were screened with the Patient Health Questionnaire (PHQ-9).

2.4.7. Patient health questionnaire for adolescents (PHQ-A)

The PHQ-A (modified by the developers for adolescents) is a 9-item self-administered measure that assesses severity of depression on a 4-point scale (0 = not at all to 3 = nearly every day) in children aged 11–17 (Johnson, Harris, Spitzer, & Williams, 2002) Sample items include “feeling down, depressed, irritated, or hopeless” and “little interest or pleasure in doing things.” A score of 5 represents mild depression and a score of 20 represents severe depression. The PHQ-A has satisfactory sensitivity and specificity (Johnson et al., 2002).

2.4.8. Patient health questionnaire (PHQ-9)

The PHQ-9 is a valid and reliable self-administered depression module that scores 9 items from DSM-IV depression criteria rated on a 4-point scale (0 = not at all to 3 = nearly every day) (Kroenke, Spitzer, & Williams, 2001). Sample items include “feeling down, depressed or hopeless” and “feeling tired or having little energy.” A score of 5 represents mild depression and a score of 20 represents severe depression. A PHQ-9 score ≥ 10 has 88% sensitivity and specificity for major depression (Kroenke et al., 2001).

In addition to the 3-tiered screening process, children and parents that reported mental health concerns or those identified by care coordination staff as potentially needing mental health services were directly referred for additional mental health screening.

2.5. Preventive interventions

The CHECK Behavioral Health Stepped Care Model was designed to be consistent with mental health promotion interventions that modify risk and promote protective factors that are linked to important determinants of mental health. We implemented several developmentally targeted mental health preventive interventions. First, online self-directed emotion regulation curricula were offered to all CHECK families. One curriculum consisted of online modules that included content about the importance of managing stress, mindfulness skills, emotion regulation skills, and distress tolerance skills (Bissel, Marko, & Van Voorhees, 2016; Van Voorhees, Watson, Bridges, et al., 2010). Separate modules for specific chronic conditions (e.g., prematurity, asthma, sickle cell disease, and diabetes) also had emotion regulation content embedded in the disease modules. Second, all CHECK parents with children aged birth – 18 years of age were offered age-appropriate parent skills DVDs corresponding to the age range of each child in their home including, The Happiest Baby on the Block, The Happiest Toddler on the Block, and Strengthening Families (Karp, 2012; Strengthening Families Program, 2017). Parents of infants (aged birth to 1 year) received a DVD that provides techniques for soothing the newborn infant to support parental self-efficacy and positive parent-child relationships. Parents of young children aged 1–6 years received a DVD with techniques for parenting toddlers and young children. Parents of children aged 7–17 received a DVD that provides techniques for parenting children in this age range. After the DVDs were mailed to families, CHECK staff called families to ask about theDVD using a 9-item questionnaire. Sample questions included: “were you able to watch the DVD?” and “what did you like about it?” The staff used the questionnaire as a guide to engage and have a conversation with families about the DVD. The data were also used for internal program evaluation.

2.6. Consultative services

The Behavioral Health Team provided consultative services to CHECK community health workers (CHWs) and other professionals (e.g., primary care providers, legal services team, specialists) to provide support and technical assistance in the coordination and quality of care provided to children. Behavioral health staff consulted with CHECK CHWs to coordinate and integrate health and behavioral health
services. Consultation was an opportunity for behavioral health staff to stay abreast of family’s needs, and to ensure the CHWs were providing care that was inclusive of the behavioral health needs. Mental health staff and CHWs were co-located, and consultations were provided within scheduled weekly clinical rounds as well as direct staff-to-staff conversations.

2.7. Direct mental health interventions

The CHECK program implemented a variety of mental health interventions and strategies to address the mental, emotional, and behavioral needs and concerns of children and their families.

The Phone coaching intervention included providing aspects of the aforementioned skills curriculum over the phone. The phone-based intervention was designed to be a brief, simple skills training to provide some immediate response to a difficult or specific situation. This level of intervention was designed for families who needed additional support to apply the online skills training to their specific situation, but who may not be interested or able to attend group meetings or individual sessions.

Crisis intervention was provided to children or parents who endorsed items related to suicide ideation or safety issues. The Behavioral Health Team developed crisis intervention protocols (i.e., suicide, child abuse, psychiatric) for staff to follow when working with a child or family member in crisis.

The Behavioral Health Team certified trainers provided The Happiest Baby on the Block training curriculum (Karp, 2012) to all parents of infants and toddlers. The training was provided in the neonatal intensive care unit, in family’s homes, or virtually using HIPAA-compliant video conferencing technology. For parents of infants, the purpose of the training was to teach parents soothing techniques to promote infant regulation and reduce infant crying, increase parental self-efficacy and positive parent-child interactions, and to promote infant sleep (Karp, 2012). Parents were given DVDs of the program and swaddling blankets. For toddlers, the purpose of the training was to teach parents methods to promote their toddlers to be patient, improve their confidence and self-esteem, and promote communication with others (Karp, 2012).

The Behavioral Health Team’s Licensed Clinical Social Worker (LCSW) and Licensed Clinical Professional Counselor (LCP) offered brief (6–12 sessions) therapy to children and their family members. The therapy sessions were conducted on site in the CHECK office therapy room, in-patient hospital room, or virtually using HIPAA-compliant video conferencing technology. The therapist guided children and their family members to set attainable individually tailored, short-term therapeutic goals. The therapist often used solution-focused, cognitive behavioral therapy, and motivational interviewing therapeutic approaches. Therapy referrals were provided for those children and families with needs beyond 12 sessions.

2.8. Referrals

The behavioral health staff provided referrals along with ongoing support and monitoring for children and/or their family members with significant mental health needs. The referral process in CHECK was approached as an intervention in itself and was an ongoing process with participants. Referrals were provided to participants whose behavioral health needs appeared unlikely to be resolvable within a six week period of brief therapy based on assessment responses and behavioral health staff clinical impressions. These were often participants who appeared to meet diagnostic criteria for DSM-V disorders or participants with any history of self-harm. The goal of referrals was to facilitate linkages to services that were accessible by the participant and where the family would be likely to remain engaged long enough to see the benefits of treatment. Referrals were identified using an online resource directory considering the participants insurance provider, preferences for schedule, transportation needs, and language needs. Once a referral was made, the behavioral health staff continued to provide follow up support to address barriers to treatment and ensure the successful connection and continued engagement in the additional services. Behavioral health staff all received training on Motivational Interviewing and Stages of Change (DiClemente & Velasquez, 2002) to assist in identifying participant internal barriers to treatment and to assist in empowering participants to take an active role in their own treatment.

2.9. CHECK behavioral health team staffing

The Behavioral Health Team was composed of a combination of lower-cost staff (e.g., bachelor-level mental health workers) and higher-cost mental health specialists (e.g., LCPs and LCSWs). Lower-cost staff conducted screenings, preventive interventions, and referrals. The higher-cost staff provided supervision to the lower-cost staff, consultative services, direct interventions, and referrals. During the first year of CHECK, psychology doctoral interns also provided mental health services. The job duties completed by mental health staff were matched to the level of licensure and professional experience. For example, licensed staff developed and have oversight of all crisis protocols. The behavioral health staff were assigned to training in a specific disease area (sickle cell disease, prematurity, and diabetes mellitus). Due to high prevalence of children with asthma, all behavioral health staff were trained in this disease area. Behavioral health staff trained in prematurity worked directly with families in the neonatal intensive care unit and staff trained in sickle cell disease worked directly with in the health clinics.

2.10. Process evaluation of CHECK program implementation

CHECK used process evaluation to gain new knowledge about the service delivery, how the services were being delivered and to whom, the barriers encountered to service delivery, and to evaluate data collection methods. We used results from the process evaluation to report outcomes to the funder and to internal stakeholders as well as to inform decisions around program refinements. We evaluated the number of mental health employees and type (i.e. licensed, non-licensed), the way data was collected and documented, the number and type of services delivered and to which patients (e.g., medical diagnosis, race/ethnicity, and age), the location of the services by type, the number and types of screenings, and interviews with staff to determine the successes and barriers they were experiencing. Based on the results of the process evaluation, we refined the delivery of mental health services to address any problematic findings from the evaluation.

2.11. Human subjects

The CHECK program was approved for data analysis under Protocol # 0235 by the University of Illinois at Chicago Institutional Review Board.

3. Results

As of September 1, 2017, CHECK had engaged and provided Tier 1 screenings to 5923 children. Table 1 summarizes the demographic characteristics of the engaged CHECK children. The children were predominantly African American (49.3%) with the remaining identifying as White (3.1%), Hispanic (27.8%), and other race/ethnicity categories (19.8%). More than a third of the children were between the ages of 6 to 12 years. The majority of the children were diagnosed with asthma (62.6%), followed by diabetes (6.1%), neurological disorders (4.6%), sickle cell disease (3.0%), prematurity (4.1%), and other diagnoses (19.6%).

As of September 1, 2017, a total of 31,470 mental health services
were provided to children and families engaged in the CHECK program. The services included mental health screenings (12,243), preventive interventions (18,411), consultative services (7,511), direct interventions (2,443), and referral services (3,105). Of the 5,923 children engaged, 2,208 (37.2%) received a Tier 2 screening (PSC-17) and 2,944 (49.7%) parents received a Tier 2 screening (PROMIS/CHAOIS). Of the 2,208 Tier 2 screenings (PSC-17), 561 (25.4%) children received a Tier 3 (PHQ-A) and 606 (20.5%) parents received a Tier 3 (PHQ-9).

Table 2 summarizes the mental health services by disease and age. Although there were a large number of children in the sample, a significant relationship was found between type of mental health service and disease ($X^2 (15, N = 5923) = 3,853.80, p = .001$) and age ($X^2 (9, N = 5923) = 193.68, p \leq .001$). Children received proportionately different types of mental health services based on their type of chronic medical condition. For example, children with asthma received a significantly larger amount of preventive interventions compared with children with other diagnoses, whereas children with prematurity and sickle cell disease received more consultative services compared with other diagnoses. Children birth to five was the second largest age category (27.6%), yet they received the highest amount of preventive services. Although the smallest age category was children and youth 18 and older, they received far less services in all mental health service categories compared with all age categories. For example, they account for 15.2% of the children and received 823 consultative services compared with children in age category 13–17 (20.6%), the second smallest age category, who received 1,608 consultative services.

As of May 2018, the Behavioral Health Team has distributed 2,077 DVDs and sent a total of 12,715 behavioral health focused text messages. A majority of those text messages were sent in mass to provide links to self-directed resources, including CHECK's online mental health modules, the national suicide hotline, and links to CATCH-IT, an online depression prevention curricula for adolescents (Van Voorhees et al., 2010). Where applicable, these text messages were also translated into Spanish and sent to Spanish-speaking participants. Additionally the CHECK behavioral health staff also began using text messaging later in the program to send referral information directly to participants who preferred to receive them via text message.

The Behavioral Health Team staffing pattern varied in the early stages of the program. At its highest staffing, the team consisted of 8 individuals (2 master's level full-time clinicians, 2 part-time doctoral students, 3 part-time paraprofessional staff, and 1 part-time director). After the initial start-up phase of CHECK, the behavioral health staffing pattern was most consistently sustained at five total staff (2 master's level licensed clinicians, 2 full-time paraprofessionals, and 1 full-time master level licensed director). The current staffing pattern has been successful in serving the mental health needs of children and families engaged in CHECK.

4. Discussion

The CHECK program is unique because it integrated mental health services into a large-scale care model of comprehensive health care delivery and care coordination program for children with chronic medical conditions. The experiences in developing and implementing the behavioral health program may be beneficial for others. Four factors that were important in the implementation of the CHECK Behavioral Health Model were the location and type of mental health services, universal mental health screening for children and their caregiver, provision of family-focused services, and the use of technology.

An essential strategy for improving pediatric mental health is to locate and position services where a child resides (Wissow, Anthony, Brown, et al., 2008). Barriers such as transportation often preclude families in engaging in mental health services (Anderson, Howarth, Vaire, Jones, & Humphrey, 2017). CHECK provided mental health services in the family's home, over the phone, through video conferencing, in the community, at health clinics, and hospitals as a strategy to offer family-focused services that mitigate barriers and offer services where the child is located. Likewise, CHECK used technology (e.g., tele-mental health) to increase families' access to mental health

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Table 1
CHECK patient demographics (n = 5923) as of September 1, 2017.

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>2783 (47.0)</td>
</tr>
<tr>
<td>Male</td>
<td>3140 (53.0)</td>
</tr>
<tr>
<td>Race/ethnicity</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>2918 (49.3)</td>
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<tr>
<td>White</td>
<td>181 (3.1)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1649 (27.8)</td>
</tr>
<tr>
<td>Other</td>
<td>1175 (19.8)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Birth to 5 years</td>
<td>1635 (27.6)</td>
</tr>
<tr>
<td>6–12 years</td>
<td>2169 (36.6)</td>
</tr>
<tr>
<td>13–17 years</td>
<td>1220 (20.6)</td>
</tr>
<tr>
<td>18– &gt; 25 years</td>
<td>899 (15.2)</td>
</tr>
<tr>
<td>Disease</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>3707 (62.6)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>361 (6.1)</td>
</tr>
<tr>
<td>Neurological</td>
<td>271 (4.6)</td>
</tr>
<tr>
<td>Other diagnoses</td>
<td>1163 (19.6)</td>
</tr>
<tr>
<td>Prematurity</td>
<td>243 (4.1)</td>
</tr>
<tr>
<td>Sickle cell disease</td>
<td>178 (3.0)</td>
</tr>
</tbody>
</table>

Table 2
Type of mental health service by disease and age.

<table>
<thead>
<tr>
<th>Diagnosis category</th>
<th>Consultative services</th>
<th>Direct intervention</th>
<th>Preventive interventions</th>
<th>Referrals</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asthma</td>
<td>2327 (31.0%)</td>
<td>1283 (52.5%)</td>
<td>11,277 (61.3%)</td>
<td>1765 (56.8%)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Diabetes</td>
<td>851 (11.3%)</td>
<td>285 (11.7%)</td>
<td>1245 (6.8%)</td>
<td>267 (8.6%)</td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td>545 (7.3%)</td>
<td>115 (4.7%)</td>
<td>813 (4.4%)</td>
<td>157 (5.1%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>1280 (17.0%)</td>
<td>469 (19.2%)</td>
<td>3619 (19.7%)</td>
<td>711 (22.9%)</td>
<td></td>
</tr>
<tr>
<td>Prematurity</td>
<td>1296 (17.3%)</td>
<td>172 (7.0%)</td>
<td>687 (3.7%)</td>
<td>71 (2.3%)</td>
<td></td>
</tr>
<tr>
<td>SCD</td>
<td>1212 (16.1%)</td>
<td>119 (4.9%)</td>
<td>770 (4.2%)</td>
<td>134 (4.3%)</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>Consultative services</th>
<th>Direct intervention</th>
<th>Preventive interventions</th>
<th>Referrals</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 5 years</td>
<td>2659 (35.4%)</td>
<td>728 (29.8%)</td>
<td>5290 (28.7%)</td>
<td>939 (30.2%)</td>
<td></td>
</tr>
<tr>
<td>6–12 years</td>
<td>2421 (32.2%)</td>
<td>935 (38.3%)</td>
<td>6795 (36.9%)</td>
<td>1206 (38.8%)</td>
<td></td>
</tr>
<tr>
<td>13–17 years</td>
<td>1608 (21.4%)</td>
<td>568 (22.3%)</td>
<td>4128 (22.4%)</td>
<td>733 (23.6%)</td>
<td></td>
</tr>
<tr>
<td>18– &gt; 25 years</td>
<td>823 (11.0%)</td>
<td>212 (8.7%)</td>
<td>2198 (11.9%)</td>
<td>227 (7.3%)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>7511</td>
<td>2443</td>
<td>18,411</td>
<td>3105</td>
<td></td>
</tr>
</tbody>
</table>
services. The mental health staff also used text messaging, which has been a successful, low-cost way to direct families to resources (Van Voorhees et al., 2010).

We conducted universal mental health screening of both children and their parents to identify mental health service needs. We found both children and their families had positive screenings and were in need of mental health services. Family-focused prevention and intervention programs, comparable to those used in CHECK, have been shown to effectively reduce a range of negative mental health outcomes and mediate familial stress that often accompanies caring for a child with a chronic condition (Leslie, Mehus, Hawkins, et al., 2016; Lippold & Jensen, 2017). Family-focused mental health prevention interventions are critical to building parenting skills, lowering stress, addressing challenging child behaviors, and strengthening parent-child relationships. Importantly, collaboration between general healthcare providers, primary care pediatricians, and specialty physicians also is vital in identifying and managing mental health problems among children (Wissow, Anthony, et al., 2008; Wissow, Gadomski, Roter, et al., 2008).

The CHECK program was developed to incorporate the aforementioned components along with addressing the gaps in service delivery to children and youth with chronic medical conditions residing in the Chicago area. Health and behavioral health services are often uncoordinated and provided in different locations. All children had an assigned CHW that worked directly with the behavioral health team to deliver care, and the teams were collocated in the same office space to enhance communication. CHECK also had onsite and access to general pediatricians and other subspecialty physicians. Many of the behavioral health services in Chicago are clinic based and do not provide in home services. Also, care coordination in Chicago is predominantly provided by phone. The location of where services were conducted was unique compared with other care coordination programs in Chicago. CHECK delivers services over the phone, via telehealth, and in-person in clinics, hospitals, homes, and in the community. Many mental health programs only provide interventions to children who meet diagnostic criteria for a mental health disorder which is often a requirement to meet “medical necessity”. Uniquely, CHECK provides services to children and families based on need and not diagnostic criteria. Although family-focused interventions have been recommended in the literature, often programs are restricted by funding/billing limitations and only provide services to one identified family member and not the entire family. CHECK offers mental health services to the child and any family member or caregiver.

4.1. Lessons learned and recommendations

The CHECK mental health program has experienced a number of challenges, including hiring and credentialing (i.e., evaluation of qualifications of licensed professionals for their job title and duties) of staff and documenting services. The first was the lengthy hiring and credentialing process. Initially, the university’s credentialing processes were very difficult to navigate because CHECK’s program was so different to what had previously been offered at the university. As a result, for eight months psychology doctoral externs using their school internship status were the only mental health staff allowed to provide therapy to children and their families. The behavioral health staff worked with the university leadership to ultimately clarify how CHECK behavioral health staff fit into the credentialing process, which resulted in all behavioral health staff providing services to children and families in accordance with their individual levels of training and licensure. The CHECK Behavioral Health Team structure did not change after resolution of the credentialing process for CHECK staff. Describing the menu of CHECK mental health services to internal and external partners was difficult since the CHECK mental health program was so different from traditional mental health fee-for-services. In the second year of CHECK, we developed four service categories (preventive interventions, consultative services, direct interventions, and referrals) to assist in describing and tracking service delivery. Lastly, the care management software used in CHECK was a challenge for the behavioral health staff. The program software did not collect data that was reflective of the mental health services. For example, the software did not track interventions provided to both the child and parent. CHECK created a system to document within the child’s chart, but a formal software that allows for documentation of the specific services provided by the behavioral health staff would be beneficial.

CHECK was funded as a demonstration project which allowed us to continuously evaluate and adjust our processes, services, and implementation to improve efficiency and enhance the quality and quantity of mental health services. Based on our evaluation, we made substantial modifications to the implementation of the behavioral health component of the CHECK program. The two areas that changed were the documentation and provision of services. Initially, staff tracked behavioral health services by listing each service on an excel spreadsheet. As time progressed, the types of specific services provided to families increased to 26 unique types of activities. Tracking this amount of activities on a spreadsheet was extremely time consuming and complicated, and we found inaccuracy and inconsistency in reporting. Another implication of tracking services in this manner was that it became increasingly difficult to measure and communicate the Behavioral Health Team’s accomplishments. In year two, the care management software used for healthcare coordination was modified to improve documentation of mental health services and the software’s reporting features were better utilized to track service delivery. This decreased the amount of staff time spent on documentation and increased the amount of services provided to families. Leadership was also able to run productivity reports on individual staff and the overall team. We also collapsed services into broader categories to improve evaluation of service delivery, increase the focus on patient-facing activities, and enhance the communication about the Behavioral Health Team’s work internally, to the funder, and potential future payers. The categories (i.e., Preventive Interventions, Consultative Services, Direct Interventions, and Referral Services) were selected to reflect the STATE Medicaid billing categories for behavioral health under Medicaid Billing Rule 132 (Illinois Department of Human Services, 2018). These categories were also entered into a web-based graphical data interface that allowed leadership and other users to view behavioral health service delivery data in real time. Services could be viewed at the broader categorical level (i.e. direct intervention) or at the level of the specific type of service offered (i.e. crisis intervention).

Behavioral health service delivery also was evaluated and improved throughout the project. During the initial stages of the project the majority of the team’s focus was on program development activities and assessment completion. Due to the aforementioned issue with the university credentialing, doctoral students were the only staff who provided direct interventions such as individual therapy to families. As the project continued to enroll families, more behavioral health needs were identified, and it became increasingly apparent that the amount of direct interventions needed to increase to meet family’s needs. We focused our efforts on navigating and resolving credentialing process as well as communicate the unique behavioral health approach of CHECK to university leadership. These efforts resulted in provisions that allowed for other behavioral health staff to offer direct intervention and therapy services to families.

During the course of the project, input from staff and families was utilized in decision making and program improvement efforts with the goal of ensuring both efficient use of staff time and resources as well as improving patient care. The input was especially useful in some of the preventive services offered to families such as the use of age-based DVD resources. Initially it was thought that providing parenting skills DVDs to all program participants would be a way to ensure they were all provided additional support and resources around behavioral health. A large number of DVDs were purchased and mailed to families based on the age of the child and address information provided by their insurer.
A substantial number of DVDs were returned to CHECK due to incorrect address information. The Behavioral Health Team quickly developed a brief questionnaire to attempt to measure the value of the DVDs to the families. We completed the questionnaire with families who were sent a DVD and it had not been returned to CHECK, and of those, less than half reported actually receiving it and only a small number reported watching it. Of those who watched, most reported finding the information valuable. Participants were also given the option to receive the same resource electronically (through an email code) in an effort to remove the potential barrier of DVD as a format, but none of the families expressed interest in viewing the information online. The use of qualitative questions assisted CHECK staff in understanding in greater detail the needs, experiences, and desires of the families. Based on this quick evaluation, input from staff, and most importantly feedback from families, it was determined that the practice of sending DVD resources in mass was costly and ineffective. We stopped sending DVDs, and instead staff sent a DVD after confirming with a family that they had the means and interest to watch it. Also at times, staff integrated watching portions of the DVD into face-to-face interactions (i.e. parenting skills group or individual therapy session). Similarly, CHECK had developed online modules around mindfulness and other emotion regulation skills early in the program. While it appears the modules were accessed from time to time, the amount of time users spent on the modules suggested they were not reading the material. We recommend that future efforts around self-directed resources focus on utilizing already existing, relevant, and reputable online resources that are easy to access, can be consumed in short periods of time, and focus on practical application of skills.

The 3-tiered assessment process is a key area that requires programmatic change. We recommend selection of different screening instruments and simplifying the assessment process. Behavioral health staff were able to identify children and families who had mental health needs through the assessment process, however the instruments were not adequate in determining the full range of needs and were limited in who and what was assessed. For example, the Tier 3 assessments, the PHQ-A and PHQ-9, are only focused on depressive symptoms and limited to children aged 11 and older and adults. Also, the PSC-17 screens children aged four and older, and as a result, children younger than age four were not screened. Children aged birth to three should receive social emotional screening for early identification and intervention for concerns and problems. Many children may already receive screening during pediatric well-child visits, but improved collaboration with behavioral health staff could provide a streamlined assessment process. Behavioral health staff supplemented the information gathered through the instruments by asking additional questions based on their clinical experience to obtain a more complete appraisal of participants needs.

The 3-tiered assessment process that involved triggering to different tiers was far too complex and confusing. The assessment process can be streamlined and simplified by eliminating the tiered process CHECK created. We recommend implementing universal screening for any potential mental health problem and/or concern in both children and their parents. Also, it is recommended that every child is screened with one instrument based on his/her age. For example, for children aged 4–17 use the PSC-17, which detects problems overall in children and has three subscale areas. For parents, an initial assessment could include some brief screening questions to identify any potential mental health concerns and any history of mental health needs or treatment. If a potential mental health need in a child and/or parent is identified, then it is recommended that the behavioral health staff use additional comprehensive and individualized screening and assessment instruments specific to the identified need, age, and presenting symptoms. For example, if a child age 15 screens positive on the PSC-17 with a high internalizing subscale, administering PHQ-A would provide additional information related to possible depression. Although, in a sense, this recommendation is a tiered screening process because needs are initially identified then additional tools may be administered. However, because children and their families require individualized assessment we recommend procedurally only one screening tool and the follow-up screening/assessment tools be selected by the behavioral health staff based on clinical presentation. The CHECK Behavioral Health Team is in the process of revising the universal mental health screening process, procedures, and instruments used.

The Behavioral Health Team delivers mental health services in conjunction with the Healthcare Team that is comprised of CHWs who deliver comprehensive healthcare management and coordination. Initially, the Healthcare Team did not receive any mental health training, however it became apparent based on families’ needs that providing additional training to the Healthcare Team would likely increase their skills and competencies in their positions. Program-wide comprehensive mental health trainings were provided to assist staff in better identifying mental health needs and working with families experiencing those challenges. Both teams are trained in Mental Health First Aid, Motivational Interviewing, Trauma Informed Practice, and several other key mental health trainings. Since the training implementation, the Healthcare Team has increased identification of concerns related to mental health in families which has resulted in more referrals and consultations with the Behavioral Health Team. The training also seemed to increase the confidence and competency of the CHWs in identifying and supporting mental health related issues, particularly issues that are impacting children’s health. The training has facilitated better communication and coordination between the two teams. Also, CHWs have reported they are better equipped to respond to the stigma that often keeps individuals from connecting to mental health providers. We recommend that CHWs receive at least basic mental health training and Motivational Interviewing training because it increases their skills in identifying needs in families and enhances delivery of care coordination.

CHECK was funded by the Center for Medicare & Medicaid Innovation (CMMI) in the Centers for Medicare & Medicaid Services (CMS) to test promising innovative payment and delivery system models to reduce program spending and improve the quality of care for Medicare, Medicaid, and the Children’s Health Insurance Program beneficiaries. A condition of the award was the development of a long-term sustainability plan and payment model for the CHECK program after the end of the funding period, which was August 31, 2018. During the past year, CHECK leadership has focused our efforts on development and planning for sustainability after the grant funding. Sustainability efforts have included securing funding from Medicaid Managed Care Organizations to continue to provide mental health services and health care coordination to children with chronic medical conditions. An important part of the sustainability has been shaping the CHECK model of care based on the lessons learned during the demonstration project implementation. The aforementioned lessons learned have been a vital part of our program revision to improve service delivery and address families’ mental health needs. After the completion of the grant aims and funding, the CHECK program has been successful in securing funding and transitioning to a market place comprehensive delivery model of care.

4.2. Conclusion

Early identification, prevention, and intervention of MEB disorders and problems can influence a child’s developmental trajectory across the life course and improve outcomes for children, families, and society (National Research Council, 2009). CHECK used a stepped care model for mental health screening and services that was integrated into a large health care delivery model for children with chronic medical conditions. Services were individually tailored and provided to children and their families via phone, video conferencing, and in-person at health clinics, hospitals, the community, and in family’s homes. The CHECK Behavioral Health team has provided a total of 31,470 services to 5923.
children and their families. During the course of implementation, se-
veral important lessons were learned and changes were made, in-
cluding developing a strategy to navigate the university credentialing system,
improving data collection efforts to increase efficiency and pro-
ductivity, simplifying the screening and assessment process as well as
comprehensive mental health screening of children and youth of all
ages, cross training CHWs in mental health to increase early identi-
fication of mental health needs families and enhance their care delivery
skills, and focusing staff time on delivery of patient facing services.
CHECK merged behavioral health and health services in order to obtain
improved care and address unmet needs, and this promising model has
the potential to inform the development of future integrated service
delivery models for children with chronic medical conditions.

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Author declaration of interest statement

The authors have no potential conflicts of interest to declare.

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