

**Title:** *Implementation of a Family-Centric Chronic Care Model for Pediatric and Adolescent ADHD in a General Pediatrics Setting*

**Collaborators:** Benjamin N. Fogel<sup>1</sup>, Deepa L. Sekhar<sup>1</sup>, James G. Waxmonsky<sup>2</sup>, Daniel Waschbusch<sup>2</sup>, Banku Jairith<sup>1</sup>

Departments of (1) Pediatrics and (2) Psychiatry Penn State College of Medicine

**Abstract:** Attention Deficit Hyperactivity Disorder (ADHD) is one of the most commonly occurring behavioral health disorders with annual costs approaching \$80 billion dollars. It has been well-established that ADHD is best treated using a chronic care model. Yet, it has proved challenging to implement such models in primary care where most ADHD treatment is delivered. Over the past year we conducted a local needs assessment to understand barriers to family-centered ADHD care at our practice. Nationwide and in our own system, three of the major hurdles in ADHD management have been assessment of medication efficacy using validated scales, integrating ADHD behavioral therapy into the treatment plan, and sustaining parent and patient engagement. We propose to create a family-centered, chronic care model (FCCCM) that integrates established components of a multidisciplinary care team and standardized treatment measures with the innovative components of electronic visits (e-visits), systematic assessment of parental factors influencing treatment uptake and a brief primary care-based engagement intervention. We will employ the Institute for Healthcare Improvement Model for Improvement and rapid Plan-Do-Study-Act cycles to implement the interventions described above in the context of a multidisciplinary, quality improvement infrastructure that is well established at Penn State Pediatrics. The primary outcome will be our capacity to meet the American Academy of Pediatrics' established metrics for appropriate treatment, medication titration and medication maintenance of ADHD as a chronic condition.

## Table of Contents

1. Goals and Objectives	3
i. Project Rationale	3
ii. Objectives	4
2. Current Assessment of Need	4
i. National Trends in ADHD Care	4
ii. Assessment of Need Within Our Own System	6
3. Target Participants and Recruitment	8
i. Primary Participants	8
ii. Recruitment	8
iii. Participant Commitment	8
iv. Benefit to Participants and the Community	8
v. Sustainability	8
4. Project Design	9
i. Program Overview	9
ii. Addressing Established Need	11
iii. Measurements of Success	11
5. Existing Projects	12
6. Timeline	12
7. Dissemination of Results	12
8. Additional Information	12
9. Organization Detail	13
10. References	16
11. Letter of Commitment – Institution	19
12. Letter of Commitment – Margaret Sibley, PhD	20

## Main Proposal

### 1) Goals and Objectives

i) Project Rationale: Attention deficit hyperactivity disorder (ADHD) produces an annual economic burden of \$15,000 per child.<sup>1</sup> With 11% of American youth diagnosed with ADHD, the annual societal cost broaches \$80 billion.<sup>2</sup> Most ADHD care is provided in primary care,<sup>3,4</sup> where reassessment rates are problematically low and depend on a burdened parent reaching out to a primary care provider (PCP). Not surprisingly, the mean treatment duration and number of annual follow-up visits are well below recommended standards by the American Academy of Pediatrics (AAP).<sup>3,5,6</sup> Primary care based quality improvement projects (QIPs) implementing the AAP guidelines<sup>7</sup> and using integrated behavioral health services improve outcomes for elementary school children with ADHD.<sup>8-12</sup> Even in these models, uptake of some evidenced-based principles, e.g. regular use of validated rating scales, remains low.<sup>6</sup> Moreover, no QIP for adolescent ADHD has been tested, so benefits beyond age 12 are unknown.

Past QIPs for ADHD have had more impact on symptoms than functioning.<sup>9,10,12</sup> One reason may be that prior QIPs primarily focused on increasing medication use with very low rates of therapy referrals.<sup>6</sup> Medication alone has a limited impact on functioning,<sup>13,14</sup> and QIPs integrating behavioral therapy into primary care have produced more success.<sup>10-12</sup> However, these models have largely relied on fixed therapies that cannot adapt to the needs of the families and did not systematically assess parental factors influencing treatment uptake and efficacy. A wide variety of family factors have been found to impact initiation and engagement with ADHD services,<sup>15-18</sup> from parental strain and psychopathology to perceptions of treatment efficacy and tolerability. These factors have not been systematically measured to inform treatment in a primary care setting.<sup>4</sup>

An internal review of Penn State Pediatrics found that we met AAP goals for diagnosis and treatment of new ADHD patients and number of annual contacts with ongoing patients.<sup>7</sup> However, most follow-up contacts were variable in timing and unstructured, with assessment left to individual provider practice style. We also found low rates of referral to behavioral therapy and had no strategy in place to promote family engagement with care.

Our goal is to create a family centered chronic care model (FCCCM) for ADHD. Like an umbrella, FCCCM is a flexible but encompassing program designed to assess needs in a standardized fashion and link families to evidence-based and desired care. It begins in primary care with treatments added in a stepped fashion so that each patient has a unique care plan created using a consistent process across providers. Its core components will be creation of a multidisciplinary ADHD care team, practice wide training in FCCCM, standardized follow-up assessment, telehealth (phone and/or electronic [e-visits]) visits to reduce burden and collect just-in-time data, systematic assessment of parent variables predicting treatment uptake and a brief engagement intervention delivered in the primary care setting (see Figure 1). Aims are consistent with Penn State Health's mission of improving access to quality care while educating the region's providers. We hypothesize that FCCCM will improve the capacity of our pediatrics clinic to meet AAP recommendations for managing ADHD (AAP action statements 4-6), focusing on the Request for Proposal's (RFP) process measures of medication titration follow-up and maintenance and appropriate treatment plus the outcome measures for improvement.

ii) **Objective 1:** *To examine the capacity of FCCCM to increase implementation of the AAP's guidelines on the treatment of ADHD as a chronic condition for patients ages 4-17 seen at Penn State Pediatrics*

Aim 1: FCCCM will increase the percentage of patients who have an assessment of response to treatment within 30 days of initiation or dose change, from 10% to 60% by 7/1/2018.

Aim 2: FCCCM will increase the percentage of patients with at least two standardized ADHD assessments each from parents and teachers in the past 180 days from 5% to 60% by 7/1/2018.

Aim 3: FCCCM will increase the percent of families referred to behavioral services from <5% to 80% by 7/1/2018.

**Objective 2:** *To evaluate the capacity of FCCCM to improve treatment engagement.*

Aim 4: We will increase the mean number of filled prescriptions over the course of a school year for children ages 4-17 prescribed medication for ADHD by 7/1/2018.

Aim 5: We will increase the mean number of behavioral sessions attended per school year for children ages 4-17 with ADHD referred to behavioral therapy in our practice by 7/1/2018.

**Objective 3:** *To examine the impact of FCCCM on patient and family outcomes.*

Aim 6: FCCCM will be associated with a  $\geq 10\%$  decrease in mean ADHD symptom severity and impairment levels rated by parents and teachers over the school year.

Aim 7: FCCCM will be associated with reduction in levels of caregiver strain over the year.

Aim 8: FCCCM will improve concordance between adolescent and parent ratings of impairment.

## 2) Current Assessment of Need

i) National Trends in ADHD Care: ADHD is one of the most common behavioral health disorders with over 1 in 10 school aged youth diagnosed with the disorder.<sup>2</sup> ADHD impairs the lives of patients, their families, and society with increased rates of academic difficulties, social struggles and family dysfunction.<sup>19-21</sup> These issues continue in adolescence and often intensify into more serious and costly problems including substance use, school drop-out and criminal activity.<sup>22</sup>

ADHD is predominantly managed by PCPs.<sup>3,4</sup> Over a third of primary care visits involve a behavioral health issue, and ADHD is one of the most common reasons medication is prescribed for children and adolescents.<sup>23,24</sup> Of all behavioral health disorders, PCPs report the most comfort with ADHD and the AAP has clear guidelines for ADHD.<sup>7,25</sup> These guidelines stress treating ADHD as a chronic condition. Core components of chronic care models include decision support tools to promote collaborative decision making, delivery systems that offer a team based approach and emphasize structured diagnostic assessments, clinical information systems promoting regular and systematic reassessment, supports to families. This is designed to educate and motivate for care, to problem solve care barriers and to link with resources both in and outside of the institution.<sup>26</sup>

Unfortunately, these principles have proved hard to apply in actual primary care settings. For example, less than 50% of practices met the guideline for a follow-up assessment within 30 days of treatment initiation and at least two follow-up contacts in the next 9

Figure 1. Structure and components of the Family Centered Chronic Care Model (FCCCM)



months.<sup>3,6</sup> QIPs primarily focusing on enhancements to delivery and clinical information systems increase implementation of the AAP guidelines.<sup>6,8</sup> Largest gains have been seen in the use of standardized diagnostic procedures, creation of written care plans, prescription of medication and frequency of follow-up assessment, but use of rating scales to evaluate response, referral to behavior therapy and families' persistence in treatment remain problematically low.<sup>6,27</sup>

Rating Scales: AAP guidelines recommend that symptoms and functioning of children be followed in an objective way, such as with validated rating scales. Yet, only 10% of children have follow-up measures completed by parents after treatment initiation and even fewer have teacher ratings.<sup>3,6</sup> Increasing use of validated scales is an area of missed opportunity but efforts must be done in a family centric way, such as administration of brief measures with capacity for off-site collection, so as to not increase the burden to families.<sup>28</sup>

Behavioral therapy services: Medication is rarely taken for extended time periods, and medication alone produces limited impact even when continued long term.<sup>5,13</sup> The impact of medication is particularly limited for academics and social skills, which are common reasons why parents present to primary care for treatment of ADHD.<sup>9,20,21</sup> Therapy treatments targeting functioning at home, school and social settings are recommended for ADHD,<sup>7</sup> yet are uncommonly used.<sup>27,29</sup> PCPs play a critical role in accessing therapy as most ADHD care begins in primary care, and families are much less likely to access therapy after medication has been prescribed, even when clear impairment persists.<sup>3,30</sup> Hence, it is essential for PCPs to discuss the value of therapy early in the treatment course and not wait for a parent to ask for it.

Engagement with care: Under 50% of referrals to behavioral health providers lead to any treatment, and rates of completed treatment are much lower.<sup>3,29,31</sup> A wide variety of family and parent factors have been found to influence engagement and persistence with ADHD treatments, including parental strain and psychopathology, motivation to change, beliefs about the type and cause of behavioral problems in their child and perceptions about treatment efficacy and tolerability.<sup>15-18,28,32</sup> Nontangible barriers such as stigma and parental strain are greater impediments than tangible ones such as clinic hours and location.<sup>31</sup>

For a chronic care model to be effective, it must provide families with supports to navigate the systems in which their children function and receive care. One option to improve engagement is to address the modifiable inter and intrapersonal barriers preventing families from attending and persisting in behavioral health treatment. Most previous QIPs have not systematically addressed these intangible barriers.<sup>8,12</sup> Brief measures exist to assess these domains and can be easily administered in primary care, and families are willing to discuss concerns about behavioral health treatments with their PCP.<sup>28,31</sup> Recent work has shown that having these discussions in the primary care setting can reduce parental strain and improve treatment uptake.<sup>11,33</sup> We propose that creating a parent profile derived from systematic assessment of parental perceptions and other intangible barriers to care can aide in identifying desirable ADHD treatments that families will persist with over time. This profile can be provided to primary care staff to guide a discussion about care using the principles of shared decision making (SDM). A single SDM session improves parental knowledge of ADHD treatments and is well received by parents and staff.<sup>34</sup> In specialty ADHD clinics, brief interventions where parents and clinicians work together to craft a care plan using SDM techniques reduces parental strain and increases uptake of behavioral services for ADHD.<sup>35,36</sup> These programs can be administered by

paraprofessionals, are brief and require few materials, making them ideal for use in primary care. However, there has been only limited evaluation of these programs in primary care, with prior trials focusing on improving uptake of medication over behavioral services.<sup>10,34</sup>

STAND (Supporting Teens' Academic Needs' Daily)<sup>36,37</sup> is an evidence-based therapy to improve the academic functioning of children with ADHD. As part of a funded National Institutes of Health grant, it has been adapted for use in primary care. STAND uses the evidence-based practices of motivational interviewing, SDM, and parent/teen behavioral contracting to optimize engagement. In STAND, parents, providers and the patient (for adolescents) are engaged as equal partners in setting treatment goals and resolving barriers to care. Maintaining treatment engagement is even more complicated when working with adolescents, but no prior QIPs have addressed the management of adolescent ADHD in primary care. Families of adolescents primarily desist ADHD care because the patient felt they did not need treatment even though the parents strongly disagreed.<sup>17</sup> Therefore, interventions to engage adolescents in treatment should attempt to reconcile differences between parent and teen's perception of the adolescent's functioning. Motivational interviewing is an ideal tool for this as it is designed to enhance awareness and therapeutic alliance while preserving the patient's voice in treatment.<sup>38</sup> Parent/teen behavioral contracting reduces parent-teen conflict, can be a means to improve concordance between parent and teen report and addresses other potential barriers to engagement while promoting adolescent autonomy.<sup>39</sup> STAND uses all of these techniques to promote engagement in the teen and parent before starting treatment.

Together with its primary author (Dr. Sibley, project consultant), we have adapted the engagement intervention from the primary care version of STAND to promote uptake of future ADHD treatment. For families of younger children, the adapted STAND intervention will consist of a single session using SDM processes to review the parent profile and motivational interview techniques to assess parental desire to change and perception of their child's level of impairment. For teens, the first session will focus on assessing and synchronizing parent/teen ratings of impairment and motivation to change using motivational interviewing and SDM. The second session will focus on reducing parent teen conflict and creation of ADHD care plan using the principles of parent/teen behavioral contracting.

ii) Assessment of Need within our own system: Hershey Medical Center is the flagship campus for Penn State Health, the only academic medical center between Pittsburgh and Philadelphia. It employs over 1,100 health care providers and runs over 1 million outpatient visits per year in 83 practice sites. Penn State Pediatrics is at the main Hershey Medical Center campus in Hershey, PA. This practice site serves approximately 13,000 patients in suburban central Pennsylvania and is staffed by 20 pediatricians, 4 nurse practitioners plus 20 pediatric resident physicians, making it the largest pediatrics clinic in the region. The patient population is 75% Non-Hispanic White, 18% African American and 7% Hispanic with 35% covered by Medicaid. The clinic is open four evenings per week and weekend mornings year-round. It has one afternoon a week of embedded psychiatry time for assessment of complex cases, two-part time licensed clinical social workers who offer therapy services, a full time social worker to assist with care management needs and two full-time nurse care coordinators to assist with patients with chronic medical issues. As a busy general pediatrics practice, it faces the same challenges as most community practices such as high flow, limited space, and multiple providers working

different days. Therefore, results of FCCCM should be widely generalizable. Ben Fogel, MD, MPH is the practice site director and Deepa Sekhar, MD, MSc oversees research efforts, focusing on behavioral health. Banku Jairath, MD leads ADHD services within Pediatrics.

Penn State Health also has a large child psychiatry division, with 24 MD and PhD faculty. The outpatient child psychiatry clinic (a short 10 minutes from Penn State Pediatrics) offers a variety of specialized ADHD programming. It is led by James Waxmonsky, MD and Daniel Waschbusch, PhD (behavioral health consultants). Child psychiatry runs the regional branch of a statewide pediatric behavioral health hotline (called TiPS) offering live guidance to community PCPs and assisting families with finding behavioral health services across the state.

A recently completed internal needs assessment found that 306 (5.6%) of patients age 6-12 seen at Penn State Pediatrics in the past year were diagnosed with ADHD, with demographics representative of nationally collected ADHD samples.<sup>40</sup> While almost all new cases included documentation of DSM ADHD criteria, including rating scales from parents and teachers, referrals for behavioral therapy were offered less than 5% of the time. The mean number of annual visits was 2.8 (S.D. 2.1) with 71.6% compliance with attended visits. Parents made an additional 4.0 phone contacts over the year (S.D. 4.1). While the number of visits met recommended thresholds,<sup>7</sup> phone contacts and office visits for ADHD follow-up care rarely included standardized assessments of symptoms or functioning.

Fifty-six (18%) families met criteria for noncompliance (defined as  $\geq 3$  missed visits per year). Multivariate logistic regression modeling found Hispanic ethnicity OR 3.49 (95% CI 1.16-10.7,  $p=0.03$ ), Medicaid insurance OR 2.01 (95% CI 1.05-3.86,  $p=0.03$ ), and co-management with psychiatry OR 3.72 (95% CI 1.75-7.81,  $p=0.001$ ) were associated with increased odds of noncompliance. We interviewed 21 (38%) noncompliant families. Those reached by phone had lower rates of comorbidity than those not reached but did not differ on other demographic variables. The primary finding was that noncompliant families reported feeling very strained by the impact of their child's ADHD. Schedule conflicts were only rated as a minimal challenge. Co-management of ADHD by pediatrics and psychiatry contributed to role confusion and poorer adherence. To address caregiver strain, the clinic devised a structured e-visit for patients on a stable medication dose. This was based on published and successful quality improvement (QI) work integrating web portal contact into standard ADHD management.<sup>41,42</sup> It incorporated validated parent and teacher rating scales and allowed parents to share concerns without the child present and at their convenience through our secure patient portal. Use of standardized scales revealed that many "stable" patients were significantly impaired by their ADHD, necessitating a treatment change.

Based on these findings and discussion with our parent advocates, we identified three initiatives to make ADHD care in our clinic more family centered. These will comprise the core components of the FCCCM. Despite regular contact with our ADHD patients, we had few formal assessment measures. FCCCM will address this by creating an ADHD team modeled after the past QIPs for ADHD<sup>8</sup> that would oversee regular reassessment of patients with ADHD to capture just-in-time data and promote more frequent treatment changes. Second, we also propose to offer 5 day a week psychiatric phone support to PCPs to promote greater onsite management of ADHD cases where the PCP remains the clear care provider rather than a shared treatment model with psychiatry. Third, we were struck by the level of strain parents reported, even in reportedly stable cases. In noncompliant cases, an office visit was viewed more as contributor

to strain than an intervention. We created a multi-faceted approach targeting parental strain by reducing the burden of office visits (offering e-visits), formal assessment of strain and other family factors precluding care and creating a brief office-based intervention using existing behavioral health resources to address these barriers and promote treatment engagement.

### **3) Target Participants and Recruitment**

i) Primary Participants: Past QIPs for ADHD have largely focused on children ages 6 to 12.<sup>8,10-12</sup>

Consistent with AAP treatment guidelines, we will expand to ages 4-17 to include the entire range of patients seen in Pediatrics for ADHD. As our internal review demonstrated deficits in maintenance care, we will include both current and newly diagnosed patients. Presently, we have 517 patients 4-17 years of age with ADHD in our practice and all will be targeted for this QIP. Patients newly identified with ADHD during the 2017-18 school year will also be included.

ii) Recruitment: All families of ADHD patients ages 4-17 in the clinic will be mailed a letter and messaged electronically through the patient portal to explain the new FCCCM and its core services. Information about FCCCM will be distributed at each well visit for eligible patients. The parent advocates will also be available to speak with any interested families about FCCCM.

iii) Participant Commitment. All aspects of the FCCCM will be integrated into the routine flow of the clinic, and all staff will be trained in it at practice wide meetings. FCCCM is designed to flexibly meet the needs of our families with ADHD while reducing the burden of care. It is not a static treatment package as adherence to those are poor.<sup>43</sup> All families will be offered the opportunity to meet with the ADHD care team, complete the parent profile, participate in e-office visits and complete the engagement intervention; however, families can decline any intervention and actual treatment is tailored to the goals of the family. To minimize burden, FCCCM utilizes stepped care starting with easily accessible and less intensive treatments. Those still evidencing impairment after initial interventions will be offered additional services, with FCCCM care coordinators available to guide families to incrementally more intensive care.

iv) Benefit to Participants and the Community: The primary goal of FCCCM is to accurately assess the needs of our ADHD families, work collaboratively with them to identify interventions to address those needs and problem-solve barriers to accessing these interventions. In accordance with the principles of family centered care,<sup>28</sup> all aspects of the FCCCM are designed to enhance benefit to the family. The process components of FCCCM (ADHD care team, written care plans, structured reassessment of functioning) have all been employed in community settings<sup>8,11</sup> and should be reproducible in our setting. The innovative components of FCCCM are e-visits, the parent profile and engagement intervention. All are designed to be brief, low cost interventions that can be run by existing staff. To extend benefit beyond our system, we have a dissemination plan to promote the benefits of systematic management of ADHD and training in the components of FCCCM. We will offer on-site, continuing medical education credentialed training on these topics to any local primary care practice (see dissemination plan).

v) Sustainability: FCCCM will not need additional non-clinic staff beyond a part-time data assistant for FCCCM start-up and to demonstrate success of the proposed QI initiatives. We have a robust data collection infrastructure for the electronic health record that can maintain the FCCCM process once established. Funds are available within our system for projects demonstrating pilot feasibility and are currently being used to promote electronic data capture in our psychiatry clinics. The data captured through this proposal will support an application for

internal funds to incorporate the core components of FCCCM directly into the medical record, alleviating the need for data assistant time. All other pediatric staff to be part of FCCCM work in the clinic, with schedule flexibility to allocate effort to this endeavor. If FCCCM demonstrates improved engagement in care, it should allow the Division of General Pediatrics to meet its departmental QI incentives generating additional funding to maintain FCCCM. The Division of Child Psychiatry, led by Dr. James Waxmonsky, has committed resources for ongoing consultation to pediatrics after the conclusion of this project.

#### **4) Project Design**

i) Program Overview: The primary goal of this QIP is to establish FCCCM, a new ADHD care system based on the chronic care model recommended by AAP<sup>7</sup> for all patients ages 4-17 with ADHD and their families treated at Penn State Pediatrics. Like an umbrella, FCCCM connects the different components of chronic care into a cohesive unit. This team's capability to effectively use the Model for Improvement to implement change is described under Organizational Detail section ii. We will redesign our delivery system to create an integrated ADHD treatment team consisting of a clinician leader, primary care ADHD champion, program evaluator, parent advocates, nurse manager, care coordinator, embedded therapists and a consulting psychologist and psychiatrist. Psychiatric services will focus on consultation to the PCP as our data found that pediatrics and psychiatry co-management reduces engagement. All clinic providers will be trained in FCCCM at practice-wide office meetings, with an emphasis on benefits to patients, families and providers. Patients will be assigned to one of 4 FCCCM teams, each led by a different FCCCM team member (2 therapists, nurse coordinator and care manager) who will be the main point of contact for assigned families. Each week, the team leader will review patient assessment schedules and collected data with data assistants to identify missing data. An FCCCM flow sheet will be created for each patient that summarizes assessment data, tracks patient contacts and records recommended ADHD treatments. The flow sheet will be part of the patient's medical record and contain summary scores for all scales. The physician champion will meet monthly with team leaders to evaluate treatment progress and reach out to the remainder of the treatment team about identified gaps.

The clinical information system will be modified to incorporate structured reassessment of ADHD symptom severity and impairment, with the option of e-visits and phone visits to reduce the burden families. As brief measures have been found to be as effective and less burdensome than longer ones for measuring treatment effects,<sup>44</sup> we have created a 5 minute reassessment battery that measures ADHD symptoms, oppositional behaviors, global impairment, common side effects and caregiver strain. The reassessment battery will consist of the 10 item IOWA Conners,<sup>45</sup> the global improvement item from the Impairment Rating Scale (IRS),<sup>46</sup> the 12 item Pittsburgh Side Effects Rating Scale (PSERS)<sup>47</sup> and the short form Caregiver Strain Questionnaire<sup>48</sup> (CSQ). These measures combined take no more time to complete than a Vanderbilt scale. At each assessment point, teachers will be sent the IOWA and full IRS scale which takes under 5 minutes to complete. Adolescent patients will complete the symptom, impairment and side effect measures. Assessment reminders will be sent out via email, phone or text with options of completing ratings by mail, phone, electronic portal or in the office. The battery will be completed at least three times over the school year, including within 30 days of every change in medication dose or initiation of a new behavioral treatment.

FCCCM will also provide an intervention to enhance family and self-management support focusing on creation of a parent profile derived from systematic assessment of parental variables impacting treatment uptake. The profile uses validated measures derived from our past work using consumer preference modeling assessing parental preferences for ADHD care (Table 1).<sup>49,50</sup> Likert ratings will be used to measure of absolute strength of preferences and rank order questions to measure relative preference for treatment. The goal of the profile is to identify efficacious ADHD treatments that are desirable to the family. Whenever possible, both parents will complete a profile with results reviewed jointly with both parents. For adolescents,

**Table 1. Components of parent and patient profile**

Domain	Measure	Rater
Knowledge of ADHD	AKOS <sup>49</sup>	P
Treatment Preferences	PAPM <sup>46</sup>	P
Barriers to Care	BTPS <sup>32</sup>	P
Parental BH Symptoms	ASRS, <sup>50</sup> CES-D <sup>51</sup>	P
Parental Strain	CSQ <sup>45</sup>	P
Motivation to Change	RtC Ruler <sup>52</sup>	P, A
Impairment	IRS <sup>43</sup>	P, A
Patient's ADHD Symptoms	DRD-RS <sup>53</sup>	P, A

AKOS- ADHD Knowledge and Opinion Survey; PPM- Parent ADHD Preference Measure; BTPS- Barriers to Treatment Participation Scale; ASRS-ADHD Self Report Scale; CES-D- Center for Epidemiologic Studies Depression Scale; CSQ- Caregiver Strain Questionnaire; RtC Ruler- Readiness to Change Ruler; P – parent; A- Adolescent

a patient profile will also be created. The profile assessments may take up to 30 minutes to complete. Part of the QIP will involve looking at completion rates and paring down the profile to optimize rate of return. Psychiatric consultants will review the profile to identify a menu of possible treatments within our system and in the community, using a stepped care approach with less intensive treatments prioritized over more intensive ones. When available, embedded services will be recommended, but the primary goal is to link the family to

the most desired service. The team leader assigned to the family will meet with the parents to discuss profile results, identify a treatment and collaboratively devise a care plan using SDM. For example, in parents reporting high strain over their child's behaviors at home, disinterest in medication but a strong belief that other parents are a useful resource, group-based parent guidance therapy will be emphasized. In accordance with SDM, additional treatment alternatives will always be discussed. The FCCCM care coordinator will work with families to find available treatments, assisted by Child Psychiatry's two dedicated care coordinators.

At this same visit, a brief engagement intervention designed to promote uptake of identified treatments will be completed with parents by the same staff member. It will be derived from STAND, an evidenced based treatment for improving academic performance in ADHD youth<sup>36</sup> (see section 2i). It will incorporate motivational interviewing to generate a collaborative discussion about how ADHD impairs the child, parental motivations for treatment and potential care barriers to advance the family's desire for change. Dr. Waxmonsky was part of a National Institute of Health grant to adapt STAND for primary care. STAND's designer (Dr. Sibley), a certified motivational interview trainer, will train staff on the engagement. The profile review and engagement intervention is designed to last 20 to 30 minutes. It is ideally completed live but can be done by phone. Booster engagement sessions can also be added.

For adolescents, a patient profile will be created that includes self-perceptions of their functioning, motivation to change and level of ADHD symptoms. Adolescent self-awareness will be measured by comparing their reports of symptom severity and impairment with parent report and objective measures (e.g. grades, school attendance). For adolescents, the engagement intervention will be expanded to two 20 to 30 minute sessions with parent and patient attending both, in recognition of the often-competing perceptions and interests of

teens and parents. As with younger patients, the first session will review the collected profiles with a focus on enhancing perception of impairments and identifying areas for change through motivational interviewing, with a goal of synchronizing adolescent and parent perception of ADHD related impairment. The second session focuses on creating a treatment contract through SDM and reducing levels of parent-teen conflict serving as care barriers through use of parent-teen behavioral contracting, an evidence based intervention for adolescent ADHD.<sup>39</sup> Parent-teen behavioral contracting promotes teen autonomy and self-efficacy by establishing parents and adolescents as equals in a collaborative relationship working toward a joint goal.

ii/iii) Addressing established Need/measurements of success:

As described in our assessment of needs, main areas for improvement to be consistent with AAP guidelines (action items 4-6)<sup>7</sup> are as follows: increasing use of rating scales for ongoing care, increasing recommendation of behavioral services, increasing parental engagement with care and reducing parental strain and the perceived burden of treatment. Process (Aims 1-5 & 8) and outcome (Aims 6-7) measures will be tracked monthly on statistical process control charts (P-charts for categorical data [Aims 1-3] and  $\bar{X}$  & S charts for continuous data [Aims 4-8]) to monitor for improvement.

a) Reassessment of care (Aims 1&2): A brief reassessment battery will be sent every 3 months or within 30 days of medication change or completion of a behavioral intervention. This will be an e-visit and will address the AAP Chapter Quality Network (CQN) process measure of medication titration follow-up and maintenance. Rating scales will be scored within a week of return and summary scores entered into FCCCM flow sheet in the medical record.

b) Behavioral services (Aims 3&5): Our goal is to identify at least one palatable and efficacious behavioral intervention for all families. If none is identified that will be explicitly stated. Recommendation of behavioral services will be documented in the visit record and the FCCCM flow sheet. This will address the AAP CQN process measure of appropriate therapy.

c) Symptomatic and functional improvements (Aims 6-8): The aforementioned scales (IRS, IOWA, CSQ) will allow measurement of change from baseline to endpoint at the patient and group level. This will address the AAP CQN outcome measure of teacher and parent-rated changes. As most patients will already be medicated at study entry, we will use a 10% reduction as evidence of success versus the 25% threshold, which is derived from studies of newly treated patients.

d) Treatment engagement (Aims 4&5): While not a formal AAP CQN metric, the extant literature has identified treatment engagement as a primary impediment to improved outcomes;<sup>7,18,26</sup> therefore, we felt it was essential to measure. The number of scripts dispensed (medical record) and number of CNS stimulant scripts filled (Pennsylvania Drug Monitoring Program Database) will be used to measure change in medication usage for all patients. An abbreviated version of the National Institute of Mental Health's Service for Children and Adolescents-parent Interview (SCAPI)<sup>51</sup> will be given at the start and end of the school year to a random selection of 20% (100) of our ADHD patients to measure use of behavioral therapy for ADHD.<sup>51</sup> The SCAPI can be completed by phone with lay interviewers in under 30 minutes.

We will also track the number of patients per week who have completed an e-visit as well as the following balance measures 1) the number of hours per week spent by clinic staff and providers sending, receiving and responding to e-visit data (tracked on log sheets 1 week

out of every month) and 2) the percentage of patients completing an e-visit who have an in person visit within the following 30 days (collected by chart review).

### **5) Existing Projects**

The Divisions of General Pediatrics and Child Psychiatry have an extensive track record of collaborations ranging from internal QIPs to external grant applications. The core project faculty (Drs. Fogel, Sekhar, Jairath, Waxmonsky and Waschbusch) have all worked together on these projects. Over the past two years, we have worked jointly to develop systematic assessment programs for pediatric depression and anxiety. This proposal will be a natural extension by expanding efforts to ADHD. Child psychiatry is currently embedded in Penn State Pediatrics, providing therapy services and consultative assessment. FCCCM will build on the existing model by having embedded therapists proactively engage families to address unmet needs and identify unrecognized barriers rather than placing the burden on parents and PCPs to identify the need for behavioral health services. Project resources will be used to add live phone access to behavioral health for PCPs and to have child psychiatry staff interpret the parent profiles. Child psychiatry has committed to continuing this support after the grant.

### **6) Timeline**

No new staff will need to be hired for this project. We have a well-established QI team that has already gathered much of the baseline data needed for this project. Therefore, we should have little difficulty assembling the team and creating the necessary system upgrades that will be part of FCCCM to meet the recommended starting time. During the first month, efforts will focus on training clinic providers in FCCCM, with goals of completing baseline assessments, patient profiles and engagement visits for all ADHD patients by month 3. The middle six months will focus on collection of at least two follow-up assessments per patient, examining the impacts of FCCCM and offering booster engagement sessions as needed, with endpoint assessments and dissemination occurring in the last 3 months.

### **7) Dissemination of Results**

Initially, we will focus on spreading FCCCM to smaller pediatric clinics within Penn State Health. This includes 8 additional PCPs and 5,000 additional patients. Through its regional phone consultation program (TiPS), the Division of Child Psychiatry has developed relationships with over 60 practices across Central and Northeastern PA. We have collaborated with the PA Dept. of Health, all 5 managed care organizations offering Medicaid plans in PA and the PA chapter of the AAP on these efforts. We will use the TiPS program and its partnerships to disseminate the value of FCCCM for ADHD across our region. With over 700,000 children in our region and a third of the TiPS calls for ADHD, we expect high demand. Dissemination efforts will also engage schools on how ADHD manifests in school, evidenced-based school supports for ADHD and the critical importance teacher of feedback in evaluating treatment effectiveness. Our nurse manager and one parent advocate plan to attend the November 2017 Children and Adults with ADHD Conference in Atlanta to present the FCCCM model and gain insight into other QIPs relevant to ADHD. We will present results at the 2019 Pediatric Academic Societies Meeting.

### **8) Additional Information: none**

## References:

1. Pelham WE, Foster EM, Robb JA. The economic impact of attention-deficit/hyperactivity disorder in children and adolescents. *J Pediatr Psychol*. 2007;32(6):711-727.
2. Visser SN, Danielson ML, Bitsko RH, et al. Trends in the parent-report of health care provider-diagnosed and medicated attention-deficit/hyperactivity disorder: United States, 2003-2011. *J Am Acad Child Adolesc Psychiatry*. 2014;53(1):34-46.e32.
3. Patel A, Mdehekar R, Ochoa Perez M, et al. Care provision and Prescribing practices of physicians treating children and adolescents with ADHD. *Psychiatric Servics*. 2017.
4. Anderson LE, Chen ML, Perrin JM, Van Cleave J. Outpatient Visits and Medication Prescribing for US Children With Mental Health Conditions. *Pediatrics*. 2015;136(5):e1178-1185.
5. Marcus SC, Wan GJ, Kemner JE, Olfson M. Continuity of methylphenidate treatment for attention-deficit/hyperactivity disorder. *Arch Pediatr Adolesc Med*. 2005;159(6):572-578.
6. Epstein JN, Kelleher KJ, Baum R, et al. Variability in ADHD care in community-based pediatrics. *Pediatrics*. 2014;134(6):1136-1143.
7. Wolraich M, Brown L, Brown RT, et al. ADHD: clinical practice guideline for the diagnosis, evaluation, and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Pediatrics*. 2011;128(5):1007-1022.
8. Epstein JN, Langberg JM, Lichtenstein PK, Mainwaring BA, Luzader CP, Stark LJ. Community-wide intervention to improve the attention-deficit/hyperactivity disorder assessment and treatment practices of community physicians. *Pediatrics*. 2008;122(1):19-27.
9. Epstein JN, Langberg JM, Lichtenstein PK, et al. Attention-deficit/hyperactivity disorder outcomes for children treated in community-based pediatric settings. *Arch Pediatr Adolesc Med*. 2010;164(2):160-165.
10. Silverstein M, Hironaka LK, Walter HJ, et al. Collaborative care for children with ADHD symptoms: a randomized comparative effectiveness trial. *Pediatrics*. 2015;135(4):e858-867.
11. Kolko DJ, Campo J, Kilbourne AM, Hart J, Sakolsky D, Wisniewski S. Collaborative care outcomes for pediatric behavioral health problems: a cluster randomized trial. *Pediatrics*. 2014;133(4):e981-992.
12. Myers K, Vander Stoep A, Zhou C, McCarty CA, Katon W. Effectiveness of a telehealth service delivery model for treating attention-deficit/hyperactivity disorder: a community-based randomized controlled trial. *J Am Acad Child Adolesc Psychiatry*. 2015;54(4):263-274.
13. Molina BS, Hinshaw SP, Swanson JM, et al. The MTA at 8 years: prospective follow-up of children treated for combined-type ADHD in a multisite study. *J Am Acad Child Adolesc Psychiatry*. 2009;48(5):484-500.
14. Swanson JM, Arnold LE, Molina BS, et al. Young adult outcomes in the follow-up of the multimodal treatment study of attention-deficit/hyperactivity disorder: symptom persistence, source discrepancy, and height suppression. *J Child Psychol Psychiatry*. 2017.
15. Charach A, Gajaria A. Improving psychostimulant adherence in children with ADHD. *Expert Rev Neurother*. 2008;8(10):1563-1571.
16. Fiks AG, Mayne S, Debartolo E, Power TJ, Guevara JP. Parental preferences and goals regarding ADHD treatment. *Pediatrics*. 2013;132(4):692-702.
17. Gajria K, Lu M, Sikirica V, et al. Adherence, persistence, and medication discontinuation in patients with attention-deficit/hyperactivity disorder - a systematic literature review. *Neuropsychiatr Dis Treat*. 2014;10:1543-1569.

18. Chacko A, Newcorn JH, Feirsen N, Uderman JZ. Improving medication adherence in chronic pediatric health conditions: a focus on ADHD in youth. *Curr Pharm Des.* 2010;16(22):2416-2423.
19. Johnston C, Mash EJ. Families of children with attention-deficit/hyperactivity disorder: review and recommendations for future research. *Clin Child Fam Psychol Rev.* 2001;4(3):183-207.
20. Baweja R, Mattison R, Waxmonsky J. Impact of Attention-Deficit Hyperactivity Disorder on School Performance: What are the Effects of Medication? *Pediatric Drugs.* 2015;17(6):459-477.
21. Pfiffner LJ, McBurnett K. Social skills training with parent generalization: treatment effects for children with attention deficit disorder. *J Consult Clin Psychol.* 1997;65(5):749-757.
22. Sibley MH, Kuriyan AB, Evans SW, Waxmonsky JG, Smith BH. Pharmacological and psychosocial treatments for adolescents with ADHD: an updated systematic review of the literature. *Clin Psychol Rev.* 2014;34(3):218-232.
23. DeMaso D. *A Guide to Building Collaborative Mental Health Care Partnerships in Pediatric Primary Care.* Washington DC: American Academy of Child and Adolescent Psychiatry; 2010.
24. Chai G, Governale L, McMahon AW, Trinidad JP, Staffa J, Murphy D. Trends of outpatient prescription drug utilization in US children, 2002-2010. In: *Pediatrics.* Vol 130. United States 2012:23-31.
25. Power TJ, Mautone JA, Manz PH, Frye L, Blum NJ. Managing attention-deficit/hyperactivity disorder in primary care: a systematic analysis of roles and challenges. *Pediatrics.* 2008;121(1):e65-72.
26. Van Cleave J, Leslie LK. Approaching ADHD as a chronic condition: implications for long-term adherence. *J Psychosoc Nurs Ment Health Serv.* 2008;46(8):28-37.
27. Visser SN, Bitsko RH, Danielson ML, et al. Treatment of Attention Deficit/Hyperactivity Disorder among Children with Special Health Care Needs. *J Pediatr.* 2015;166(6):1423-1430.e1421-1422.
28. Davis CC, Claudius M, Palinkas LA, Wong JB, Leslie LK. Putting families in the center: family perspectives on decision making and ADHD and implications for ADHD care. *J Atten Disord.* 2012;16(8):675-684.
29. Gellad WF, Stein BD, Ruder T, et al. Geographic variation in receipt of psychotherapy in children receiving attention-deficit/hyperactivity disorder medications. *JAMA Pediatr.* 2014;168(11):1074-1076.
30. Pelham W, Fabiano G, Waxmonsky J, et al. Treatment Sequencing for Childhood ADHD: A Multiple-Randomization Study of Adaptive Medication and Behavioral Interventions. *Journal of Clinical Child & Adolescent Psychology.* 2015;In Press.
31. Larson J, dosReis S, Stewart M, Kushner R, Frosch E, Solomon B. Barriers to mental health care for urban, lower income families referred from pediatric primary care. *Adm Policy Ment Health.* 2013;40(3):159-167.
32. Kazdin AE, Holland L, Crowley M, Breton S. Barriers to Treatment Participation Scale: evaluation and validation in the context of child outpatient treatment. *J Child Psychol Psychiatry.* 1997;38(8):1051-1062.
33. Hodgkinson S, Godoy L, Beers LS, Lewin A. Improving Mental Health Access for Low-Income Children and Families in the Primary Care Setting. *Pediatrics.* 2017;139(1).
34. Brinkman WB, Hartl Majcher J, Poling LM, et al. Shared decision-making to improve attention-deficit hyperactivity disorder care. *Patient Educ Couns.* 2013;93(1):95-101.
35. Chacko A, Wymbs BT, Wymbs FA, et al. Enhancing traditional behavioral parent training for single mothers of children with ADHD. *J Clin Child Adolesc Psychol.* 2009;38(2):206-218.
36. Sibley M, Altszuler A, Ross J, Sanchez F, Pelham W, Gnagy E. A group based parent-teen collaborative intervention for high school students with ADHD. *Cognitive and Behavioral Practice.* 2014;21:32-42.

37. Sibley MH, Graziano PA, Kuriyan AB, et al. Parent-teen behavior therapy + motivational interviewing for adolescents with ADHD. *J Consult Clin Psychol*. 2016;84(8):699-712.
38. Nar-King S, Suarez M. *Motivational Interviewing with Adolescent and Youth Adults*. New York: Guilford Press; 2011.
39. Barkley R, Edwards G, Robin A. *Defiant Teens: A Clinicians Manual for Assessment and Family Intervention*. New York: Guilford; 1999.
40. A 14-month randomized clinical trial of treatment strategies for attention-deficit/hyperactivity disorder. The MTA Cooperative Group. Multimodal Treatment Study of Children with ADHD. *Arch Gen Psychiatry*. 1999;56(12):1073-1086.
41. Epstein JN, Langberg JM, Lichtenstein PK, Kolb R, Simon JO. The myADHDportal.com Improvement Program: An innovative quality improvement intervention for improving the quality of ADHD care among community-based pediatricians. *Clin Pract Pediatr Psychol*. 2013;1(1):55-67.
42. Epstein JN, Kelleher KJ, Baum R, et al. Impact of a Web-Portal Intervention on Community ADHD Care and Outcomes. *Pediatrics*. 2016;138(2).
43. Graves MM, Roberts MC, Rapoff M, Boyer A. The efficacy of adherence interventions for chronically ill children: a meta-analytic review. *J Pediatr Psychol*. 2010;35(4):368-382.
44. Pelham WE, Fabiano GA, Massetti GM. Evidence-based assessment of attention deficit hyperactivity disorder in children and adolescents. *J Clin Child Adolesc Psychol*. 2005;34(3):449-476.
45. Loney J, Millich R. Hyperactivity, inattention, and aggression in clinical practice. In: Wolraich M, Routh D, eds. *Advances in developmental and behavioral pediatrics*. Vol 3. Greenwich, CT: JAI Press; 1982:113-147.
46. Fabiano GA, Pelham WE, Jr., Waschbusch DA, et al. A practical measure of impairment: psychometric properties of the impairment rating scale in samples of children with attention deficit hyperactivity disorder and two school-based samples. *J Clin Child Adolesc Psychol*. 2006;35(3):369-385.
47. Pelham WE, Jr., Carlson C, Sams SE, Vallano G, Dixon MJ, Hoza B. Separate and combined effects of methylphenidate and behavior modification on boys with attention deficit-hyperactivity disorder in the classroom. *J Consult Clin Psychol*. 1993;61(3):506-515.
48. Brannan AM, Athay MM, de Andrade AR. Measurement Quality of the Caregiver Strain Questionnaire-Short Form 7 (CGSQ-SF7). *Adm Policy Ment Health*. 2012;39(1-2):51-59.
49. Waschbusch DA, Cunningham CE, Pelham WE, et al. A discrete choice conjoint experiment to evaluate parent preferences for treatment of young, medication naive children with ADHD. *J Clin Child Adolesc Psychol*. 2011;40(4):546-561.
50. Wymbs FA, Cunningham CE, Chen Y, et al. Examining Parents' Preferences for Group and Individual Parent Training for Children with ADHD Symptoms. *J Clin Child Adolesc Psychol*. 2016;45(5):614-631.
51. Jensen PS, Eaton Hoagwood K, Roper M, et al. The services for children and adolescents-parent interview: development and performance characteristics. *J Am Acad Child Adolesc Psychiatry*. 2004;43(11):1334-1344.