



Center for the Urban Child
and Healthy Family



CENTER FOR THE URBAN CHILD AND HEALTHY FAMILY

Bi-Annual Progress Report

AUGUST 9, 2019
BOSTON MEDICAL CENTER DEPARTMENT OF PEDIATRICS

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1. Center Strategic Vision

1.1. Vision

Health equity—that *all* children have an equal opportunity to be healthy and to achieve their full potential.

1.2. Mission

Redesigning the pediatric care model to achieve dramatic improvements in outcomes for children and families facing adversity.

1.3. Approach

To build the Pediatric Practice of the Future through developing, testing and scaling an innovative model of health care delivery, working in concert with families, communities, and other child- and family- serving sectors.

1.4. Audacious Goal

By 2028, all children cared for by BMC Pediatrics are healthy and ready to learn, with adequate supports to thrive, by age 5.

1.5. Strategic Principles for Creating the Pediatric Practice of the Future

To ensure that all children are healthy and ready to learn by age five, we are developing a scalable, sustainable health care model that engages cross-sector child-serving systems to directly address the self-identified needs of families with young children. We envision a Pediatric Practice of the Future that prepares all children to be healthy and ready to learn by the age of five by:

- Empowering families to define their health priorities and design their own care
- Providing care to the family (not just the child), including addressing caregiver needs
- Providing new opportunities to promote social and emotional wellbeing; and
- Developing community partnerships—particularly with early childhood educators, in a new way that leads to deeper collaboration, to address social determinants of health

1.6. Center Pillars: What Makes Us Different?

1. Commitment to fundamental systems-level change;
2. Commitment to rigorous data collection and analyses to determine if initiatives are working and for whom; and
3. Changes to the care model are driven by voices of families.

1.7. Healthy and Ready to Learn by 5

The Center has set a goal that by 2028, all children cared for by BMC Pediatrics will be healthy and ready to learn, with adequate supports to thrive, by age 5. The rationale for this decision is that a focus on this population enables emphasis on bi-generational wellness, connection with other child serving agencies, and is a formational time for life course health. Additionally, there is national momentum within Medicaid around creating quality metrics focused on early childhood and school readiness.

2. Pediatric Practice of the Future

The Center’s first major initiative is to design, test, iteratively improve, and scale the Pediatric Practice of the Future, a new model of pediatric primary care that systematically addresses the unmet needs of low-income families and puts each child—regardless of his or her socioeconomic background, race, or gender—on a path to a healthy, resilient life.

2.1. Building the Practice through Human Centered Design

One of the pillars of our work is the belief that fundamental care redesign will only be successful if families co-create solutions. As such, our approach to designing the Pediatric Practice of the Future includes the use of human-centered design (HCD) to drive the process of system redesign and ensure sustainable system-level improvements will be desirable, usable, and accessible to pediatric primary care staff and the families they serve.

HCD is a generative, people-centered set of design methods that honors and engages families, stakeholders, and partners actively in the design process; and presumes that we will discover together new models, services, experiences, and tools that fall outside the bounds of today’s pediatrics practice. In December, we announced a new partnership with **Agncy**—a Boston-based firm specializing in HCD to reduce structural inequalities and generate actionable solutions to complex systems issues —to lead us through the process.

2.1.1. Phase 1a: Framing the Problem to Solve from the Families Perspective

In Phase 1a of the HCD work, Agncy conducted deep ethnographic work with our families, interviewing them in their homes about their definitions of health and wellness, and ways in which Pediatrics primary care could most effectively address their needs. The goal of this generative learning process was to frame the opportunities for innovation from the perspective of the families. Center Research Assistants recruited diverse families (all with at least one child less than five years of age) from our pediatric practice. We recruited a total of 14 families segmented by specific variables that we hypothesized would drive differences in our learning through the interview process (Table 1).

Table 1. Family Recruitment Segmentation							
14 Families Total							
7 Geographic Location Lives within Boston-Area				7 Geographic Location Lives Outside of Boston-Area			
3-4 Health Issues At least 2 chronic conditions on the problem list (behavioral health included)		3-4 No Health Issues 0 or 1 chronic condition on the problem list (behavioral health included)		3-4 Health Issues At least 2 chronic conditions on the problem list (behavioral health included)		3-4 No Health Issues 0 or 1 chronic condition on the problem list (behavioral health included)	
1-2 Child Age 0-2 y/o	1-2 Child Age 3-5 y/o	1-2 Child Age 0-2 y/o	1-2 Child Age 3-5 y/o	1-2 Child Age 0-2 y/o	1-2 Child Age 3-5 y/o	1-2 Child Age 0-2 y/o	1-2 Child Age 3-5 y/o

The sociodemographic variables that were part of our selection criteria included how close to BMC the family lives, and chronic child health conditions. We also had capacity to recruit in three primary languages, English, Spanish, and Haitian Creole.

The content of the two hour, in home interviews centered around the

families’ live and values, care resources, definitions of health and wellness, their healthcare experience overall, and their experience with BMC.

2.1.2. Phase 1b. Merging the Families Perspective to Systems Insights

During Phase 1b, Agncy conducted interviews and observations with BMC Pediatrics providers and staff. This research, concurrent with the family interviews, allowed Agncy to understand the perspectives of the BMC

care team and administrators, and how these perspectives overlapped or diverged with the families' perspectives.

Agncy conducted one-on-one interviews with 5 providers, and 7 staff members including Social Workers, Nurses, Family Navigators, and Medical Assistants. To supplement these interviews, they also spent time observing in the Pediatrics clinic, and shadowed one of the primary care providers.

At the conclusion of Phases 1a and 1b, Agncy analyzed all of the information they had gathered and key themes and insights were abstracted. These insights served as the guideposts for the rest of the HCD process. See [Appendix 1](#) for the family and practice insights that emerged from this process.

2.1.3 Attributes of the Practice of the Future

We have designed the Pediatric Practice of the Future with overarching **attributes** that we believe are essential to its effectiveness (and were lifted up by families as priorities during Phase 1), but are flexible enough that the **features** of this attribute can be adapted to individual practices and settings. These attributes and features have been designed with scale and sustainability in mind. Of note, each attribute will align with specific process metrics.

Through the [co-creation process](#), we were able to start to build out the features informed by what resonates with the experience of families. Over the remainder of the summer, we will be fully building out the features within these attributes, informed by the co-creation process, and these will be the core components of the model that we will [pilot and test](#) beginning in January.

The following represent what we believe to be emerging as core attributes:

1. Embedded economic mobility services
2. Options for care content and delivery that are customizable, yet offered in a systematic way
3. Care and services within and outside of health care assessed and streamlined
4. Opportunities to bolster social networks
5. Using technology for health promotion and communication, coordination and integration with community based organizations
6. Developing a holistic approach to the resiliency and wellness of the *family*
7. Impact of structural racism and economic oppression, is acknowledged and mitigated and incorporated into care practices
8. Intentional and systematic approach to workforce development that empowers all employees to operate at the highest level of their skillset

2.1.4. Phase 2. Co-Creation of the Ideal Experience

During Phase 2, Agncy translated the insights and learning from Phase 1 into a concept for the ideal experience in the Practice of the Future. From these experiences, we developed a model that can be prototyped, iterated, and refined.

During co-creation workshops families, providers, staff and leadership collectively identified other opportunities for a new model of care. Our emerging framework focuses on supporting resilient family development through: building the skills to empower families beyond their health; recognizing that families and caregivers grow along with their children; and a focused and relevant perspective on development. During the remainder of the summer and fall, the Center team, in partnership with Pediatrics primary care, will be creating an implementation plan around these frameworks that will be piloted in clinic at the beginning of 2020 (see [Practice of the Future Pilot](#)).

2.2. Piloting the Practice of the Future

Beginning in January 2020, the Center will deploy an innovation team to pilot the new model in the BMC pediatrics clinic. This innovation team will include care team members already embedded within our clinic (e.g. nurse, medical assistant, administrative coordinator and social worker), as well as new roles including a Community Wellness Advocate, a physician team lead, a scale and sustainability consultant and an Innovation Improvement Advisor. The Pediatric Practice of the Future will function as a standalone clinic within primary care, and will enroll 30-50 families with infants to follow longitudinally. Deep community partnerships—with shared accountability for families—will facilitate efficient, streamlined care directed by families' needs. The innovation team will engage in rapid tests of change, led by the Innovation Improvement Advisor who has quality improvement expertise. Based upon routine data collection, the innovation team will iteratively improve the model, with the goal of expanding the number of families included over time.

2.3. Measurement

The Center has set a goal that by 2028, all children cared for by BMC Pediatrics will be healthy and ready to learn, with adequate supports to thrive, by age 5. In order to design the Practice of the Future that makes progress toward this goal, we have established a driver diagram to outline the key outcomes to assess progress over time toward goal ([Table 2](#)).

The Center is establishing a baseline of Healthy and Ready to Learn by extracting and analyzing the measures listed in [Table 2](#) from the electronic medical record (EMR) for the entire pediatric primary care panel of children ages birth to 6 years of age. Additionally, Center Research Assistants are conducting primary data collection in the clinic by administering a brief questionnaire to parents with children ages 3-5 years old. The survey will allow us to assess children's social emotional health and parental attachment and self-efficacy which are not readily extractable from the EMR, but that we think are critical to children's ability to be healthy and well.¹ The Center will be disseminating a baseline report in August.

Once the Practice of the Future is launched, we will routinely collect data both on participating families and on a sample of families receiving care within our regular primary care clinic (matched for factors such as child age). Measures will assess the drivers listed in [Table 2](#) as well as other key indicators of model impact ranging from child health service use to cost of care for child (and ideally parent) to satisfaction with care delivery to provider burnout.

¹ The Center created the primary data collection survey using validated questions from three validated instruments: FLOURISH Questionnaire; the National Survey of Children's Health (Section G); and the Parenting Sense of Competency Scale (PSOC).

Table 2. Drivers of Healthy and Ready to Learn by Age 5 Mapped to Key Outcome Measures

Primary Drivers	Secondary Drivers	Measures
Physically and emotionally healthy child	Physical, emotional and developmental health needs identified and addressed	Normal development (using validated screening tool) or referrals/support if concerns; early intervention referrals; fully immunized; normal BMI; no iron deficiency or appropriate therapy if deficient; screening and referrals for behavioral health concerns; child emergency department utilization; child hospitalizations; cost of care to the health system for child (short and long term)
Quality early childhood education	Literacy opportunities at home	Curious about learning; number of days a week parents read to children; school ready
	Ability to enroll in accessible, low/minimal cost child care	Placement in high quality early education
	Opportunities to promote social-emotional learning at home	Able to bounce back from setbacks; School ready; Daily routine includes opportunities to promote social and emotional health
Safe, stable and nurturing relationships	Parental access to their own medical and behavioral health care	Screened for mental health needs and connected to services, as needed; has primary care physician; employed or in school (as appropriate); rapid repeat pregnancy; cost of care to the health system for parents (short and long term)
	Parent/caregiver understanding and application of parent-child interactions to support healthy development	Strong parent-child connection
Safe physical environment	Food security	THRIVE (social determinants of health) screening results
	Housing security	THRIVE (social determinants of health) screening results
	Economic mobility	THRIVE (social determinants of health) screening results

3. Integrated Evaluation Core

The Boston Accountable Care Organization (BACO) Research Team and the Center have partnered to build a comprehensive evaluation core that spans the Center and BACO that can support “soup to nuts” evaluation across Pediatrics and the hospital. We are working closely with clinical and programmatic teams to create the evaluation infrastructure to promote both quality improvement, and to answer key questions about the impact of these clinics and programs on patient outcomes. The strategic aims of the evaluation core are to:

- Create a culture of evaluation by building forward-thinking program evaluation into the design of new programs
- Facilitate understanding of how programs are working, and for whom
- Provide early focus on scalability and financial sustainability
- Drive evaluations that align with broader Health System priorities and goals.
- Support robust and innovative evaluation designs to facilitate increased publication opportunities.

At the beginning of June, we welcomed Eliza Hallett, MS as Research and Evaluation Coordinator to the team. She will serve as the lynchpin between the evaluation efforts of the Center and BACO and help move forward the work of the core.

Currently, the Center and ACO Research projects are being used as “learning labs” to assess evaluation needs, understand data access operations, and establish data governance processes. This will lay the foundation for optimal data systems and capacity that are necessary to launch a full-service evaluation core.

3.1. Progress on Evaluation of Existing Programs

As part of the evaluation core, the Center provides oversight for the evaluations of innovative clinical programs within the Pediatrics Department (with a focus on the programs that were first funded by the Center). Over this year, we have made significant progress in our evaluation efforts. We are currently providing programmatic and evaluation support to the SOFAR program, EASE program, and evaluation support to the CATALYST program. Below we have detailed progress on each.

3.1.1. Supporting Our Families through Addiction and Recovery (SOFAR) Program

Launched through seed funding from the Center, the Supporting Our Families through Addiction and Recovery (SOFAR) program is a trauma informed, non-stigmatizing medical home for substance exposed families in pediatric primary care to promote safe, stable, and nurturing relationships. The program is led by Medical Director Eileen Costello, MD and pediatrician Sara Stulac, MD, MPH. To date, the program has served over 125 families.

The Center has worked with the SOFAR team to identify priority process and outcome measures. We are also creating a standardized visit questionnaire to enhance uniform data collection across the SOFAR patient population. We have completed an IRB-approved retrospective chart review and analysis of all 69 mother infant dyads seen in SOFAR during the first year of the program (see [Appendix 2](#) for data table). In March, the SOFAR team submitted a manuscript to the journal *Current Problems in Pediatric and Adolescent Health Care*.

3.1.2. Engagement and Access to Special Education (EASE) Program

Launched through seed funding from the Center, the Engagement and Access to Special Education (EASE) program aims to provide education and guidance to address the current gaps in the resources for patients and families with special education needs. Primary Care Providers refer children to the program if there are concerns about educational progress. Providers from the EASE program work closely with the family, school and primary care provider to support children’s learning needs. The program is led by pediatrician Soukaina Adolphe, MD and Manager of Family Navigation, Ivys Fernandez-Pastrana, JD, and has served over 180 children since its inception.

The retrospective chart review and analysis of the 93 patients seen in the EASE program in the first year is complete. Additionally, the team has been obtaining consent to enroll patients in prospective data collection which is ongoing. The Center team has supported the program in formulating their research questions and ensuring the quality and integrity of the data collected. The EASE clinic team presented their innovative clinic model at the 2019 Pediatric Academic Societies (PAS) meeting (see [Appendix 3](#) for data table).

3.1.3. CATALYST Program

The Center for Addiction Treatment for Adolescents / Young adults who use Substances (CATALYST) is a substance use treatment program based in both the BMC Adolescent Clinic and General Internal Medicine. CATALYST utilizes an Office-Based Addiction Treatment (OBAT) model that is developmentally-appropriate for youth patients. Patients are adolescents and young adults who use substances, including opioids, marijuana, and alcohol. The CATALYST clinical team is interdisciplinary and includes a nurse care manager, physicians, social workers, recovery coaches, and patient navigators. Depending on the patient, treatment plans may include current evidence-based medications for addiction and co-occurring psychiatric disorders, psychotherapy, Hepatitis C treatment, pre-exposure prophylaxis for HIV, contingency management, and

assistance with recovery needs such as transitional assistance, food security, and employment and residential programs.

Overarching goals are to reduce or eliminate substance use, reduce harm from substance use, improve health and well-being, and maximize engagement and retention in care. The Center and the BACO Research team are working collaboratively to evaluate the CATALYST program. We have recently received IRB approval for the retrospective chart review of the first two years of the clinic. The Clinical Data Warehouse is extracting this data and analysis will begin in July.

4. Urban Health and Innovation Fellowship

The Center is committed to providing continuous learning opportunities to advance the development of providers, improve the systems they are working in and ultimately provide better care. Currently we are achieving this aim through the development of the Urban Health Innovation Fellowship.

The overarching goal of this two-year Fellowship program is to develop a cadre of pediatric innovators capable of creating large-scale change for families' health. We expect that program graduates will seek a variety of career opportunities in government, public health, for profit and non-profit sectors, and academia. Once launched, we anticipate bringing on one to two fellows per year for a two-year fellowship.

Currently, the Center is working with a Curriculum and Evaluation Consultant from the Boston University School of Public Health to design the fellowship curriculum with a focus on preparing future leaders in pediatric healthcare transformation. The fellowship is a two year program in which the first year is focused on applied learning within the three core competencies (Design and Evaluation of Program and Policy, and Leadership and Management, Systems Innovation). Year two is focused on the fellowship project, likely in partnership with a community agency that the fellow identifies.

By the start of 2020, the Fellowship curriculum will be developed and we will be accepting applications for the summer/fall 2020 cycle.

5. Other Initiatives

5.1. Pediatric Family Advisory Board

The Pediatric Family Advisory Board (FAB) was launched by the Center for the Urban Child and Healthy Family in 2017 with the goal of fostering parent, child and professional partnerships to better meet the needs of families receiving care at Boston Medical Center. Regular engagement with the FAB ensures that families are at the center of planning and development of innovative new models of care and is aligned with the adage "nothing about us without us."

Through monthly meetings, the FAB works closely with the Center to provide advice on the design of the Pediatric Practice of the Future. Over the last year, the FAB has seen prodigious growth. In addition to active participation in monthly meetings, the FAB has also contributed to the planning of and participated in community events including the BMC Wellness Day, and the Peace of Mind Family Festival.

Currently, the FAB is undergoing in active recruitment with a goal of expanding its membership by 5-6 members by the end of 2020. We have also expanded our language capacity in this year and can now recruit families who are English and Spanish speaking.

5.2. Trauma Informed Care Working Group

Trauma-informed care approaches are a foundational component of the Pediatric Practice of the Future. Therefore, the Center convened on several occasions a group of inter-disciplinary thought leaders who have a vested interest in creating trauma informed spaces across a variety of sectors in Massachusetts. The Center tasked this Trauma Informed Care Working Group with generating a list of actionable recommendations for pediatric practitioners to be more trauma informed in their daily practice.

In recent years, trauma informed care has established a framework for how providers and entities across social service sectors can better serve individuals who may have experienced trauma. While national groups like the Substance Abuse and Mental Health Services Administration (SAMHSA) have published frameworks for integrating trauma informed approaches into organizations, to our knowledge, there is a paucity of resources that provide guidance on how pediatric professionals can put these frameworks into action in their day-to-day work.

To fill this gap, the Trauma Informed Care Working group developed 18 Recommendations for Integrating Trauma Informed Approaches into Pediatric Practice. These recommendations can be universally implemented with all patients, regardless of whether the practitioner is aware of a specific trauma history. Additionally, while created for healthcare, these recommendations could be modified and applied to a variety of other family serving sectors.

5.3. The Joel and Barbara Alpert Endowment for Children of the City

Through the Joel and Barbara Alpert Endowment, the Center supports medical students from the Boston University School of Medicine as well as pediatric residents from Boston Medical Center to implement and evaluate projects that innovate and transform pediatric health care delivery and improve child health outcomes. Pediatrics fellows are also invited to submit more traditional small research grants. We have now released two Requests for Proposals in fall 2018 and spring 2019. Through this grant we funded two projects in the fall cycle (see below). Submissions for the spring cycle are currently under review with awards being announced in August.

5.3.1. Efficient Strategies for Triage and Preventive Intervention for Children Referred to for Diagnostic Autism Evaluations: A Feasibility Study

Due to a number of factors, screening, diagnosis, and provision of services to children with autism spectrum disorder is often delayed, especially among low-income and ethnic minority families. Two General Pediatrics academic fellows have designed a feasibility study to test an innovative screening method for more streamlined diagnosis of autism spectrum disorder in pediatrics. Study investigating the feasibility, acceptability, and preliminary impact of implementing an innovative screening method for diagnosis of autism spectrum disorder in pediatrics. The aim of the study is to contribute valuable information on implementation processes, screening tool accuracy, and parent and provider attitudes that will be critical for clinical decision-making at BMC as well as for future studies designed to evaluate screening and diagnostic processes for low income and ethnically diverse pediatric populations

5.3.2. Transportation and Health: Improving Access to Healthcare for Pediatric Patients through Rideshare

Transportation barriers have been identified as an impediment to health care access, particularly among vulnerable populations. This project supports pediatric residents to implement and evaluate a pilot intervention where Uber rides are offered to patients experiencing transportation insecurity. The project will evaluate the impact of offering Uber rides through UberHealth to asthma patients with exacerbated

symptoms, on patient health outcomes, and utilization of more costly health services (emergency room, ambulance, etc).

6. Dissemination

6.1. Publications

In September, we launched a **quarterly newsletter** that is disseminated internally to the BMC community and externally to our donors, stakeholders, and community collaborators. Stories published in any of our newsletters can be [found on our website](#).

Children and Families of the Opioid Epidemic: Under the Radar Issue

Journal of Current Problems in Pediatric and Adolescent Health Care

Authors: Sara Stulac, MD, MPH, Megan Bair-Merritt, MD, MSCE, Elisha M. Wachman, MD, Marilyn Augustyn, MD, Carey Howard, MPH, Namrata Madoor, BA, Eileen Costello, MD

Accepted for Publication

[School Readiness: The Next Essential Quality Metric for Children](#)

Published July 18, 2018 in the Health Affairs blog

Authors: Carey Howard, MPH, Charles Homer, MD, MPH, Melissa Gillooly, MPP, Bob Vinci, MD, Megan Bair-Merritt, MD, MSCE

[Reimagining Pediatric Care](#)

Published August 31, 2018 in the Boston University School of Public Health Public Health Post

Authors: Carey Howard, MPH, Bob Vinci, MD, Melissa Gillooly, MPP, Megan Bair-Merritt, MD, MSCE

6.2. National Presentations

Engagement and Access to Special Education Clinic: Innovation in Primary Care

Pediatric Academic Societies (PAS) Meeting 2019

Presenters: Soukaina Adolphe, MD; Ivys Fernandez-Pastrana, JD

April 2019

Supporting Our Families through Addiction and Recovery: The SOFAR experience at Boston Medical Center

2019 AAP National Conference & Exhibition

Poster Presenter Author: Sara Stulac, MD, MPH

Co-Authors: Eileen Costello, MD; Megan Bair Merritt, MD, MSCE; Marilyn Augustyn, MD; Carey Howard, MPH; Namrata Madoor, BA

October 2019

Building the Pediatric Practice of the Future: Care Innovation for Families Facing Adversity

2019 AAP National Conference & Exhibition

Poster Presenting Author: Carey Howard

Co-Authors: Megan Bair-Merritt, MD, MSCE; Melissa Gillooly, MPP, Robert Vinci, MD

October 2019

A Dyad Model of Care for Mothers and Children of the Opioid Epidemic

American Academy of Child and Adolescent Psychiatry Chicago, IL

Presenter: Eileen Costello, MD

October 2019

7. Grant Highlights

7.1. Seeding Innovative Partnership Grant from the Boston Foundation

In April 2018, the Center, BMC Vital Village Network, and Economic Mobility Pathways (EMPath) were awarded a yearlong planning grant from The Boston Foundation. EMPath, a Boston based non-profit, disrupts poverty by using Mobility Mentoring®, a brain science informed coaching model that helps people develop the skills and capacity to achieve upward economic mobility. EMPath Mobility Mentors utilize the Bridge to Self Sufficiency® as a comprehensive tool to guide families through the process of achieving their long term economic and personal goals related to family stability, well-being, education, financial management, and career management. Through this collaborative Boston Foundation grant, BMC and EMPath aim to improve health outcomes for families facing financial hardship while simultaneously strengthening the relationship of these two entities working toward a common goal.

A central element of developing this partnership was providing BMC and the Vital Village Network staff with a deep understanding of EMPaths' approach, while providing EMPath staff with much greater familiarity with the challenges and opportunities of operating in the context of a health care delivery system serving vulnerable populations. During this planning year, some Family Navigators from pediatrics and Breastfeeding Scholars from the Vital Village Network have received training in Mobility Mentoring®, while EMPath staff have had the opportunity to observe patient flow through obstetrics and pediatrics. The partnership is also working closely with BMC's StreetCred team to consider how to best integrate this initiative with other offerings at BMC that promote financial well-being and address material hardships.

The outcome of this award has been for BMC, through the Vital Village Network Breastfeeding Coalition, to join the Economic Mobility Exchange. The Exchange is a community of organizations and government agencies learning about EMPath's Mobility Mentoring® model. In the coming year, we will test the impact of Vital Village Network Breastfeeding Scholars implementing Mobility Mentoring®.

7.2. CAPLAN Foundation for Early Childhood

In January, the Center was awarded a yearlong grant from the CAPLAN Foundation for Early Childhood which allowed us to fund a portion of the Human Centered Design work conducted in partnership with Agncy. Specifically, this award allowed the Center to engage Agncy in Phase 2 of the process to lead families and the practice through the co-creation sessions that identified the opportunities for design of the Practice of the Future.

Appendix 1. Family and Practice Insights

Family Insights	
Theme	Description
Parenting is an N-of-1	Parents interviewed were isolated in their parenting experiences for a range of reasons.
Parents are problem-solvers	Parents are responsive. They're in a constant loop of problem spotting, solution identification, and acting on this solution.
Parents think of health and wellness differently	Definitions of wellness and health varied significantly across families. While every parent focused on physical health and well-being, other parents built upon this to include additional aspects. Of note, almost all families cited spiritual wellness and relationship with God in their conception of wellness
Parent values were surfaced through two themes heard in almost every interview (food and money)	Through these two topics, we were able to understand what parents value (and often lack) in their lives and experiences: <ul style="list-style-type: none"> • Control • Autonomy and choice • Tangible feedback • Clarity or comprehensibility
Goals vs. plans	All families had goals but there was a distinction between parents who were meeting goals and those who were not and a desire for support with setting goals, planning around those goals, and adapting to unplanned circumstances.
Parents work toward progress indicators	Our parents understand their child's well-being and growth against a very limited and specific set of progress indicators, most commonly weight gain and reading level .
Practice Insights	
Theme	Description
A strong "do" muscle	Practice culture is one of empowerment, ownership and accountability. Agency noted a uniform and powerful sense of personal responsibility in each person's description of how their role contributes to meeting the needs of patients and families.
Scrappy and responsive to needs	This sense of personal ownership is reflected by the means that team members take to support families. Staff and providers are navigating multiple systems, building case-by-case connections and systems know-how. There is the sense that --perhaps too often-- the team is figuring out how to bend systems to the needs of their families rather than finding agile, flexible mechanisms in place.

Deeply relational	Staff and providers are nurtured by the relationships they build with families. We heard a number of common themes in how the team does this critical relational work.
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Appendix 2. SOFAR Clinic Retrospective Data Tables

INFANT CHARACTERISTICS

Table 1. Characteristics of Infants in SOFAR Clinic during Year 1, July 11, 2017 – July 11, 2018 (N=69)

	N (%)
Gender	
Female	35 (50.72)
Delivery method*	
Caesarian	26 (39.39)
Vaginal	40 (60.61)
NICU admission*	
Yes	20 (30.30)
No	46 (69.70)
Proportion who received pharmacotherapy for NAS by type	
Methadone	32 (46.38)
Phenobarbital	8 (11.59)
Clonidine	3 (4.35)
Morphine	1 (1.45)
Age in months at end of year 1	
0-2	11 (15.94)
3-6	13 (18.84)
7-12	22 (31.88)
>12	23 (33.33)
Foster care status among infants during year 1	
Never in foster care	53 (76.81)
Ever in foster care	16 (23.19)
Non-kinship foster care	10 (62.50)
Kinship foster care	6 (37.50)
In foster care at end of year 1	13 (18.84)
Frequency of most common primary clinic visit diagnosis	
Feeding or GI	11 (15.94)
Developmental	6 (8.70)
Respiratory	10 (14.49)
Other	56 (81.16)
Reported living situation of SOFAR infants ever during year 1	
In a recovery home	
With relatives or friends	27 (39.13)
In own home/apartment	16 (23.19)
In a shelter	11 (15.94)
In a shelter	13 (18.84)

*Data for delivery method and NICU stay are not available for 3 infants who were not born at BMC

Table 2. WHO-Age Standardized Weight-for-Height Percentile Categories at 3 months, 6 months, and 9 months of SOFAR Infants

Percentile Categories	N = 56, N (%)	N = 49, N (%)	N = 32, N (%)
	3 months	6 months*	9 months
≤5 th	10 (17.86)	1 (2.04)	1 (3.13)
5 th to ≤10 th	11 (19.64)	2 (4.08)	3 (9.38)
10 th to ≤25 th	3 (5.36)	12 (24.49)	4 (12.50)
25 th to ≤50 th	14 (25.00)	8 (16.33)	5 (15.63)
50 th to ≤75 th	10 (17.86)	10 (20.41)	6 (18.75)
75 th to ≤90 th	5 (8.93)	7 (14.29)	4 (12.50)
>90 th	3 (5.36)	8 (16.33)	9 (28.13)

*Missing information for one child who was assessed at 3 months and at 9 months

MATERNAL CHARACTERISTICS

Table 3. Characteristics of Mothers of Infants in SOFAR Clinic during Year 1, July 11, 2017 – July 11, 2018 (N=68)

	N (%)
Proportion of Mothers with a Diagnosis of Hepatitis C Ever During Year 1*	50 (73.53)
Proportion of Women With Self-Reported Mental Illness by Diagnosis*	
Depression	20 (29.41)
Anxiety	20 (29.41)
PTSD/Trauma	8 (11.76)
Bipolar disorder	7 (10.29)
ADHD	3 (4.41)
Other	3 (4.41)
Proportion of Mothers of SOFAR Infants on Medication Assisted Treatment (MAT), Assessed at Child's Birth*	63 (95.45)
Methadone	34 (53.97)
Buprenorphine	28 (44.44)
Naltrexone	1 (1.59)

*Hepatitis C Diagnosis Data not available for 1 Mother

*Mothers could have reported more than one mental illness so percentages will not add to 100%

*MAT data missing for three women and unavailable for two women who did not deliver at BMC

Appendix 3. EASE Clinic Retrospective Data Tables

Table 1. Demographic characteristics of children seen in the EASE clinic from August 2017 to March 2019 (N = 93)*

	N (%)
Proportion of children with active IEP ever during data abstraction period	
Yes	53 (56.99)
No	22 (23.66)
N/A (Too young to enroll in school)	17 (18.28)
Data not available	1 (1.08)
Age at intake	
0-2 years	19 (20.43)
3-15 years	69 (74.19)
16-22 years	5 (5.38)
Gender	
Male	68 (73.12)
Female	25 (26.88)
Race	
Black / African American	57 (61.29)
White / Caucasian	8 (8.60)
Asian	1 (1.08)
Declined / Not available	8 (8.60)
Ethnicity	
Not Hispanic or Latino	68 (73.12)
Hispanic or Latino	25 (26.88)
Grade in school at intake	
Pre-K	8 (8.60)
Kindergarten	3 (3.23)
1 ST -8 TH	44 (47.31)
9 TH -12 TH	7 (7.53)
N/A (Too young to enroll in school)	17 (18.28)
Not enrolled in school	3 (3.23)
Data not available	11 (11.83)
Primary Diagnosis at the first EASE clinic visit**	
ADHD	20 (21.51)
Global developmental delay	36 (38.71)
Autism	15 (16.13)
Learning disability	16 (17.20)
Data not available	7 (7.53)
Insurance type	
Medicaid Insurance	67 (72.04)
Private Insurance	7 (7.53)
No Insurance	3 (3.23)
Insurance Unknown	16 (17.20)

*Eligibility criteria for analysis was having a complete consent form from each patient. There were additional patients seen in the EASE clinic during the time frame but only those with fully completed consent forms (N = 93) were included in the analysis.

**One patient has 2 primary diagnoses so percentages will not add to 100

Table 2. Primary diagnosis by age at intake of children seen in the EASE clinic from August 2017 to March 2019 (N = 93), N (%)

	0-2 years (n = 19)	3-15 years* (n = 69)	16-22 years (n = 5)
ADHD	0 (0.00)	18 (26.09)	2 (40.00)
Global developmental delay	12 (63.16)	22 (31.88)	2 (40.00)
Autism	3 (15.79)	12 (17.39)	0 (0.00)
Learning disability	1 (5.26)	15 (21.74)	0 (0.00)
Data not available	3 (15.79)	3 (4.35)	1 (0.00)

*One patient has 2 primary diagnoses so percentages will not add to 100

Table 3. Primary diagnosis by gender of children seen in the EASE clinic from August 2017 to March 2019 (N = 93), N (%)

	Male* (n = 68)	Female (n = 25)
ADHD	15 (22.06)	5 (20.00)
Global developmental delay	23 (33.82)	13 (52.00)
Autism	14 (20.59)	1 (4.00)
Learning disability	10 (14.71)	6 (24.00)
Data not available	7 (10.29)	0 (0.00)

*One patient has 2 primary diagnoses so percentages will not add to 100