FIRST 1,000 DAYS SUNCOAST: REGIONAL INITIATIVE TRANSFORMING CARE FOR BABIES AND THEIR FAMILIES

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Abstract
A child’s first 1,000 days are a period of rapid brain development; negative environments and stressful events can impact their lifelong health, well-being, resiliency, and prosperity. First 1,000 Days Suncoast is a tri-county initiative in southwest Florida comprising 90 partner organizations supporting families and babies by connecting them with resources and tools through a large and comprehensive network. Following the Collective Impact model, the region’s public community hospital was designated as the backbone organization, with a nurse-led team guiding the operations. A steering committee, with leaders of regional nonprofits and foundations, ensures tactical alignment with county priorities, and has been key in building a strong partner infrastructure. Three key components guide the activities of the initiative: care coordination; parent empowerment; and targeted interventions. Through collaboration with community professionals and parents, the initiative identifies the most pervasive barriers to care for families and develops innovative solutions. This method has led to system-wide transformations, organization-specific enhancements, and process improvements.

Keywords: community partnerships, care coordination, technology-community partnerships, lived experience, protective factors, social determinants of health, integrative activities

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INTRODUCTION

With 80% of brain development occurring by age two, what happens during the first 1,000 days can impact a child for the rest of their life (National Scientific Council on the Developing Child, 2020; Roxas, 2021). When those early years are characterized by adversity, the lifetime effects can be devastating. Chronic stress can affect brain function, inflammation, and metabolism, resulting in inflammatory conditions, mental health/developmental disorders, obesity, and hypertension (Evans & Kim, 2013). Anxiety and stress during pregnancy are associated with premature deliveries, low birth weight, and lasting effects on a child’s health, temperament, and behavior (Ramos & Dunkel Schetter, 2018). Having a parent with a mental health diagnosis, poverty, living in an unsafe neighborhood, and lack of primary care provider have been associated with behavioral issues in young children (Bitsko et al., 2018).

Fortunately, children are extraordinarily resilient if given support to help them thrive (National Scientific Council on the Developing Child, 2015). Building protective factors such as concrete support, social connections, and parental resilience has been shown to foster healthy development in children and has been a framework woven into preventive programs (Child Welfare Information Gateway, 2020). Research has shown that supporting prenatal and early childhood programs is one of the best financial and population health investments a community can make, leading to better long-term educational, health, and economic outcomes (Miller, 2015; Garcia et al., 2019).

The First 1,000 Days Suncoast initiative was launched in southwest Florida by the Charles & Margery Barancik Foundation in 2018 to strengthen the systems of care for families during their child’s first 1,000 days (Charles & Margery Barancik Foundation, n.d.). The foundation convened leaders, facilitated discussions, raised funds, and cultivated donor relations. Recognizing the disparities in health outcomes for parents experiencing poverty, homelessness, substance use disorders, racism, and other
inequities, the initiative brought together health-care providers and nonprofit organizations through a Collective Impact model (Kania & Kramer, 2013). Relationships and collaboration are the foundation, driving force, and pulse of First 1,000 Days Suncoast. By fostering partnerships, the initiative not only supports families, but strives to build a strong sense of camaraderie among dedicated professionals.

Prior to launching First 1,000 Days Suncoast, surveys and interviews with parents and professionals reported silos and “difficulty navigating the system” as some of the biggest barriers to care for families and agencies. Striving to move from a maze of resources to a coordinated system of care, First 1,000 Days Suncoast has deepened partnerships, built region-wide technology infrastructure to enhance care coordination, empowered parents, and developed targeted solutions to better serve families. A plan for change with three key components (care coordination, parent empowerment, and targeted interventions) was developed, providing a broad yet flexible structure for activities, goals, and priorities. These components have been driven by dynamic partnerships built through the Collective Impact model (Kania & Kramer, 2013), led by a small team of integrators.

COLLECTIVE IMPACT AND INTEGRATIVE ACTIVITIES

First 1,000 Days Suncoast was designed using the Collective Impact model, which aligns agencies with a collaborative mission, vision, and purpose (Kania & Kramer, 2013). The elements of the model are a common agenda, shared measurement, mutually reinforcing activities, continuous communication, and backbone support (Kania & Kramer, 2013). Backbone support requires the designation of one agency to lead the day-to-day operations and the collaborative systems-level work. Research supports the idea that interorganizational alliances enhance communication, trust, and respect, while also dispelling misconceptions, supporting population health, and generating innovative solutions for communities (Kania & Kramer, 2013; Woulfe et al., 2010; Mays et al., 2016). One of the initiative’s first operational accomplishments within the model
was the development of a steering committee comprising professionals and parents with lived experience in struggling to navigate social and health-care services. Governance by this diverse and vested team proved important in maintaining the initiative’s credibility and safeguarding alignment with regional activities.

The backbone organization for First 1,000 Days Suncoast is Sarasota Memorial Health Care System in Sarasota, Florida. More than 4,500 babies are born at this health-care system every year; almost half are born to families who are either uninsured or have Medicaid insurance. The system’s extensive reach provided many opportunities for intervention and support. Integrative activities were incorporated into the health-care system’s role as the backbone agency, which includes focusing on equity, building inclusive and strong workgroups with professionals and parents, connecting mission and merit, and enhancing inter-organizational collaboration between health-care organizations and community agencies (Chang et al., 2020). In 2019, Sarasota Memorial hired a family nurse practitioner with a doctorate in nursing practice to lead the initiative. Creating a strategic plan, developing evaluation methods, building a governance structure, growing the partner network, and including parents’ lived experiences in navigating community services were among this professional’s early accomplishments. From 2021 until 2023, the addition of new team members expanded the initiative’s marketing campaigns, parent education and support, navigation services, and regional networking and partnerships. By measuring the connections, partnerships, agency enhancements, and activities, the initiative has gained valuable information about the vital role played by the First 1,000 Days Suncoast team as community integrators (see Figure 1).
Steering committee chair, Dr. Kameron Hodgens, shared her appreciation of the hospital’s dedication to serving its most vulnerable community members:

Watching SMH (Sarasota Memorial Hospital) take on this amazing program and be the hub of coordination has been incredible. Expanding a traditional hospital health care system to true community care and coordination feels like the next frontier for creating and sustaining a healthy community. (K. Hodgens, personal communication, August 27, 2023).

COMPONENT ONE: CARE COORDINATION

Up to 80% of a person’s health is impacted by social determinants of health (SDoH), such as housing, food, access to services, etc. (Hood et al., 2016). Research has also shown that addressing these determinants not only improves population health outcomes but can also decrease societal health-care expenses (Taylor et al., 2016).
During pregnancy, prenatal distress and pregnancy anxiety are risk factors for premature births (Dunkel Schetter et al., 2022). Ramos and Dunkel Schetter (2018) found that the most common pregnancy stressors were panic about being a good parent, lack of prenatal care, limited social support, financial concerns, and fear for one’s own health. To reduce this stress, the initiative built a local web of support for families through its nonprofit partner network. Connecting families with these resources enables parents to focus on their relationship with their child (Center on the Developing Child at Harvard University, 2016).

In 2020, First 1,000 Days Suncoast invested in advanced technological infrastructure by purchasing a cross-sector collaboration software called Unite Us. Unite Us facilitates closed-loop electronic referrals and provides an up-to-date resource directory and efficient case management communication. Input from partner organizations on selection and vetting of the platform by the health-care system invoked a sense of trust and security among nonprofits. Unite Us not only improves care coordination, but also highlights strengths and challenges in the community with data about referrals, outcomes, and health equity. These data are actionable and can be used to inform local investments and to improve outcomes for individuals, providers, and the community.

**Backbone Agency Implementation and Impact**

Women and Children’s Services at Sarasota Memorial Health Care System has played a pioneering role in health-care innovation. Utilizing the Unite Us platform, nurses and case managers sent 7,895 referrals and assisted 3,358 families in accessing services from August 2020 to October 2023. Universal SDoH screenings for every pregnant patient and follow-up wellness calls after delivery provided a comprehensive approach, ensuring families had the support they needed. The successful pilot in Women and Children’s Services led to system-wide implementation across Sarasota Memorial Health Care System, one of the largest public health-care systems in Florida, with two hospitals (one 120 bed and one 901 bed), network of urgent care centers, a free-standing...
emergency care center, and a 400+ provider multi-specialty medical group. Research is being conducted by Sarasota Memorial Health Care System and Unite Us on the impact of social care coordination on maternal and infant health-care utilization and health outcomes (readmissions, admissions, and emergency department visits).

**Family Navigation Program**
Listening to the voices of parents who shared “difficulty navigating the system” as a top barrier to care, First 1,000 Days Suncoast built a family navigation program to support parents in connecting to resources. A Unite Us assistance request form on the First 1,000 Days Suncoast website enables parents to quickly enter their needs. A Family Navigator then reaches out directly to families and refers them to support services and resources across the community.

From January to October 2023, the Family Navigator assisted 264 families, resulting in 800 referrals to community partners. Twenty members of those families participated in interviews. The feedback was overwhelmingly positive, and informants expressed levels of satisfaction, gratitude, and appreciation. When asked to share one to two words about their experience, the following themes were identified: 70% felt relieved and/or supported; 70% felt grateful; 40% felt more connected to their community; and 35% felt hopeful.

The first thing was relief! Thank God! … I don’t have family in this country. [First 1,000] is more like family help, like friends helping me solve problems. Otherwise, I wouldn’t have known about organizations, have (had) someone to share my concerns with, etc. It was a great relief to me. (Mother helped by First 1,000 Days Suncoast, personal communication during interviews)

In the 15-20 minute phone interviews, a staff member from First 1,0000 Days asked a series of questions about their experience. The parents highlighted the importance of being connected to various resources, such as food assistance, utility support, breastfeeding clinics, parenting classes, and childcare, helping to alleviate financial
burdens and providing other support. The mention of prompt, friendly, positive interactions with outside organizations suggested that the First 1,000 Days Suncoast partner network fosters a welcoming and supportive environment.

...[I]t’s very hard to find the resources, to know which website to go to, and then how to start (the) process to receive benefits. It made my life less stressful, when I was already stressed with learning how to take care of a new human being. After receiving services, I felt happy and grateful. (Mother helped by First 1,000 Days Suncoast, personal communication during interviews)

Data-Driven Solutions and Capacity Building
A team of community leaders, many of whom serve on the First 1,000 Days Suncoast steering committee, review Unite Us data to identify community barriers, capacity concerns, and opportunities, all with an emphasis on health equity. Through analysis of co-occurring needs, partnership ideas have surfaced to create a centralized place with multiple services to better support families. Providing one location with multiple services available is critical, as transportation remains another top barrier reported by families. Rejection rates and unresolved cases, along with missing supportive services give an overview of the health of the local network. Reviewing this information uncovers ways to improve coordination and prompt responses from professionals with trackable outcomes. In the future it is hoped that this team will provide recommendations to elected officials, philanthropic institutions, and other community leaders about allocating resources and developing programs to better assist high-risk families.

COMPONENT TWO: PARENT EMPOWERMENT

Supporting responsive relationships between parents and children is a key principle for improving health, behavioral, and developmental outcomes. Responding appropriately to a child’s cues not only assists with development but lets them know they are safe
and important. For the parent, responsive relationships improve confidence and offer a sense of hope (National Scientific Council on the Developing Child, 2015; Center on the Developing Child at Harvard University, 2021). This information prompted the launch of the initiative’s campaign to provide tools and resources for parents during their child's early years. Valuing the perspective of parents, various activities have provided them with opportunities to represent their communities and advocate for their families and neighbors and have provided a powerful way to produce innovative solutions, including authentic marketing tactics, partnership opportunities, and educational campaigns.

**Parents as Teachers**

Investing in a regional movement to encourage parents to be their child’s first teachers was a broad and equitable way to provide resources to all parents. Three interactive campaigns stemmed from this movement, with a goal of increasing awareness about supportive resources and tools available to parents.

**Color the Community.** In 2021, First 1,000 Days Suncoast sponsored murals by local artists that promoted parent-child bonding and celebrated the magic of childhood, along with sidewalk chalk activities for children.

**Plant, Grow, Bloom.** In 2022, this campaign likened brain development to the nurturing of a seed to help it grow and bloom. More than 3,000 seed packets and grow kits were distributed to several nonprofit partners to give to their clients, providing a fun, educational activity for families to do together.

**Brain-Builder Bags.** A partnership among Sarasota County Libraries, the Studer Community Institute, Suncoast Campaign for Grade-Level Reading, and Sarasota Memorial Health Care System, this program offers a gift bag for families, with tools to promote early brain development, along with a video introduction and education from nurses. More than 8,000 brain-builder bags have been given to new families since 2021.
After viewing the brief education video, 53.4% of parents reported increased knowledge on how communicating with the baby influences brain development.

**Parents as Leaders**

In 2022, First 1,000 Days Suncoast worked with 10 partner agencies to organize focus groups involving more than 140 parents. Valuable information was gathered to understand the most persistent barriers experienced by families. Participants expressed goals and dreams related to education, meeting basic needs, parenting, debt repayment, volunteering, and spending quality time with their children. Dreams for their children included happiness, good health, fulfilling employment, financial security, citizenship, a violence-free world, a strong support system, and cultural preservation. Different themes were identified, including childcare, employment, finances, support, mental health, housing, transportation, access to social services/health care, system navigation difficulties, and other challenges. These barriers have provided detailed information and a framework to build targeted interventions.

Building on the momentum of the parent focus groups, a parent advisory committee was developed in 2022 to place parent perspectives at the center of intervention design and strategy. Parents have provided guidance on long- and short-term goals; helped develop and implement activities and marketing tactics; and promoted the initiatives within their own communities. Listening to the needs of parents has also resulted in word-of-mouth referrals to services, indicating that the services are resonating. A few parents who have been a part of the advisory committee now participate in other community leadership roles such as nonprofit boards, and/or have found jobs in which they can use their own lived experience to support others. Blake Neathery, Parents for Parents program coordinator at NAMI Sarasota and Manatee Counties and First 1,000 Days Suncoast parent advisor, shared her testimonial:
... First 1,000 Days has helped me become the person I am today. They helped me get out of a crisis situation, move forward, and grow strong. After receiving services, I felt supported, empowered, and encouraged. I grew a lot because I got the support I needed and today my life is good! Through connections of the initiative, I am now a Parent for Parents coordinator, helping support families through the child welfare system. My passion is breaking generational cycles of unhealthy behaviors and relationships and now I get to help others who are struggling. (B. Neathery, personal communication, June 22, 2023).

COMPONENT THREE: TARGETED INTERVENTIONS

Following Harvard University’s Center on the Developing Child’s three-tiered approach of meeting families’ basic needs, developing broad campaigns, and creating specialized programs for high-risk families, First 1,000 Days Suncoast invested in macro-level systematic and structural changes while also developing targeted services (Center on the Developing Child at Harvard University, 2021). The interventions ranged from professional development opportunities and collaborative workgroups to innovative programs and partnerships. Using data from workgroup members, parent focus groups, and the Unite Us community dashboard, these targeted programs tackle professional, systematic, and/or family challenges.

Plan of Safe Care

In 2020, First 1,000 Days Suncoast convened key partners and facilitated the development of a regional plan of safe care (POSC) for substance-exposed newborns and their families. The purpose of the POSC is to connect pregnant individuals who are struggling with substance use to resources, and to provide ongoing coordination and support prior to and after the baby’s birth. Intake was built into the Unite Us system to enhance care coordination so that families would not have to retell their story to each service agency. Connecting pregnant individuals who have substance use disorders with support prenatally will hopefully enable more newborns to remain with their families,
and that the intensive support and care coordination will help build parental resilience and foster long-term recovery. One of the initiative’s partners, Safe Children Coalition, continues to lead the operations of this important project.

**Professional Development Workgroup**
Data from the parent focus groups revealed some of the major reasons parents were fearful of reaching out for support, including criticism or poor treatment from healthcare professionals in the past, stigma about their struggles with substance use disorders or mental illness, and Health-care professionals’ and non-clinical staff’s lack of cultural competency. To educate professionals and improve family trust, a Professional Development Workgroup was formed to plan multiagency professional development trainings on trauma-informed care provided by a partner organization, Resilient Retreat. More than 100 clinical and non-clinical professionals attended the series; 100% found the workshop to be helpful and would recommend it to others, and 93% reported their knowledge had increased.

**Perinatal Mental Health Workgroup**
First 1,000 Days Suncoast pioneered a region-wide Perinatal Mental Health Coordination Hub in February 2023. A marketing campaign was created to raise awareness and combat stigma around mental health struggles during pregnancy and postpartum. Social media ads and flyers were developed in collaboration with local therapists and parents with lived experience, that directed families to an online assistance request form that connects with the Unite Us platform. First 1,000 Days Suncoast and Healthy Start Coalition of Sarasota County then reach out to families and refer them to mental health agencies. Since the perinatal hub’s launch, First 1,000 Days Suncoast has connected more than 50 parents to mental health services, with a considerable number learning about the hub through the social media campaign. Engaging with community obstetricians and nurse midwives, nurse practitioners, pediatricians, nonprofit organizations, and health-care leaders, the initiative has increased awareness about

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the perinatal hub, which has led to more routine screenings for depression and anxiety across the community. Workgroup chair Carla Johanns shared the value of the perinatal hub for her organization and parents:

Without First 1000 Days we wouldn't have had as many opportunities to connect families to resources...Our involvement with the initiative (First 1,000 Days Suncoast) got us also recognized as a perinatal mental health provider. We increased training and became more robust in helping that population. Partnerships strengthen our work, our focus and makes us better prepared to serve our families. (C. Johanns, personal communication, September 11, 2023)

**Navigator Workgroups**

Many local nonprofit organizations and health-care agencies hire ‘navigators’ (e.g., community health workers, peer advocates, care coordinators, family navigators, social workers) to help connect families struggling with complex social and medical situations to local resources. These professionals work tirelessly to uncover resources to help some of the most vulnerable families in the region. Assisting families can be emotionally draining; in a local survey conducted by Resilient Retreat (n.d.), 50% of helping professionals reported symptoms of compassion fatigue.

First 1,000 Days Suncoast recognized the need for networking, communication, and collaboration among professionals to better support them. At the monthly workgroup meetings, navigators discuss complex cases, learn about community services, and network with their peers. Within the first six months, there were reports of increased professional knowledge of community resources, improved peer connections, development of new interagency partnerships, and the resolution of complex client scenarios (see Figure 2).
CONCLUSION

First 1,000 Days Suncoast was launched in 2018 to improve coordination of and access to care for families and their babies. By leveraging community partnerships and applying integrative activities, the initiative promoted child-parent relationships and empowered parents to be community leaders, improved care coordination among medical and social services, and pioneered targeted interventions.

For its first five years, First 1,000 Days Suncoast has focused on governance structure, building tactical partnerships, technological infrastructure, and strategic development, laying a solid foundation for future efforts. Moving with the pulse of the community and
employing aggressive yet flexible strategies to engage with partners have been key. As the initiative works collectively within the region, it will continue to deploy its approach of using shared data, empowering parents, and collaborating with community organizations to identify pervasive regional barriers and to unveil unique community solutions. The initiative seeks to help break cycles of abuse, promote healthy parent and child relationships, and improve family resilience — all leading to a healthier, more productive society.

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References


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Chelsea Arnold, DNP, APRN, FNP-BC, received a Bachelor of Science in Biology from the University of Florida, a Bachelor of Science in Nursing from the University of Central Florida, and a Doctor of Nursing Practice with a concentration in Family Practice from Florida State University. She is a board-certified Family Nurse Practitioner and has a certification in Trauma and Resilience from Florida State University as well as a certificate in Diversity, Equity, and Inclusion in the Workplace from the University of South Florida. Dr. Arnold oversees the operations, strategic planning, and evaluation of First 1000 Days Suncoast. Prior to her current role, Dr. Arnold worked as a Family Nurse Practitioner at the Sarasota County Health Department. Treating some of the most vulnerable residents in the community, she saw firsthand the impacts of social determinants of health and the struggles families faced navigating services. Her passion is building relationships: relationships between organizations to coordinate care, relationships between service providers and their clients to build trust, and relationships of parents with their children to help families thrive. She believes that collaboration among partner organizations and parents in the community is key to making a difference.

Kelly Romanoff, MPA, is Senior Vice President for Strategy and Evaluation for the Charles & Margery Barancik Foundation, in Sarasota, Florida. She was a member of the Gulf Coast Community Foundation
staff for seven years and then joined the Barancik Foundation in 2015. Her career in philanthropy began at the statewide association, Florida Philanthropic Network, where she led research and policy efforts. Kelly completed a Bachelor’s Degree and earned a Master’s Degree in Public Administration from the University of Central Florida. She is a trained nonprofit governance consultant and facilitator. Kelly was instrumental in the launch of First 1,000 Days Suncoast, convening founding partners, developing a vision for the region, and serving in numerous leadership roles. She has raised more than $2 million to support operations of First 1,000 Days Suncoast.

Mary O’Connor, MSN, RN, CCE, CSSGB, IBCLC, received a Bachelor’s Degree in Biology from New College of Florida, a Bachelor’s Degree in Nursing from the University of South Florida, and a Master of Nursing from Florida State University. She holds certification in Trauma and Resilience and Six Sigma Green Belt Certification. Her nursing background is Neonatal Intensive Care and Mother/Baby Care. In her current role as Manager of Community Outreach for Women and Children’s Services at Sarasota Memorial Health Care System (SMHCS) she expands community partnerships and serves as a liaison between SMHCS and community partners. She is responsible for the development, organization, and implementation of the Lactation Service program and for maintaining Baby-Friendly Hospital designation. She manages the Childbirth Education Program and oversees the operations of the SMHCS backbone work of First 1,000 Days Suncoast. Current areas of professional interest include implementation of trauma-informed care principles and standardization of assessment of social determinants of health in health-care settings.

Pam Beitlich, DNP, APRN, RN, NEA-BC, is the Executive Director of Women and Children’s Services at Sarasota Memorial Health Care System in Sarasota, Florida. With almost 4500 births a year at SMHCS, she is driven to raise the standard of care for both women and children in the organization’s four-county area. Pam has assisted in leading First 1000 Days Suncoast, to ensure that new mothers get the services they need to give their newborns the best beginning. Pam’s true passion is helping to foster the next generation of health-care leaders. To that end, she completed her Doctor of Nursing Practice Degree in Healthcare Systems Leadership from Florida State University in 2014. Her research project on the implementation of Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) in Labor and Delivery and the Neonatal Intensive Care Unit, published in Nursing Management, showed a 30% improvement in teamwork. Pam has won a Partnership Award from the Sarasota County Public School System for her work with them on Leadership. She has received Leadership Awards from Sarasota Memorial Health Care System and from the Florida Organization of Nurse Executives, and a Lifetime Achievement Award from Leadership Sarasota, a program of the Greater Sarasota Chamber of Commerce.

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