IMPROVING ACCESS TO PEER-TO-PEER SUPPORT FOR CAREGIVERS OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS: A QUALITY IMPROVEMENT PROJECT.

by

Caitlyn Ashley Patera

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DEDICATION

It is with genuine gratitude that I dedicate this work to the most resilient and devoted people in the world; caregivers of children and youth with special health care needs.

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ABSTRACT

Caregivers of children and youth with special health care needs (CYSHCN) experience stress, burden, and social isolation, which are powerful predictors of poor health outcomes for both the caregivers and their children. Supporting caregivers of CYSHCN in a clinical setting is critical in holistically supporting a CYSHCN medical home. The Montana Parent Partner Program (MTPPP) is an evidence-informed peer-to-peer support opportunity aimed at improving health and social outcomes for caregivers. This program is funded by the Department of Public Health and Human Services (DPHHS) and is available to Montana health care clinics that serve the CYSHCN at no cost to the clinic. At the selected practice site location (PSL), the referral rate and enrollment rate to the program were low; in November and December 2021, only two enrollments were completed into the program out of the 66 patients evaluated aged 0–21 years—a total enrollment rate of 3%. The referral rate was not historically tracked. DPHHS, the PSL, and the MTPPP partnered together in a quality improvement (QI) effort to achieve a referral rate into the MTPPP between January and February 2022 of 50%. The QI team identified barriers to referring and enrolling caregivers into the MTPPP and subsequently proposed opportunities for improvement to reach their goal. First, the team aimed to educate providers at the PSL on the evidence, benefits, and services of the MTPPP. Once the team expressed increased confidence in referring patients to the program, the team re-developed the workflow, referral, consent, and enrollment process and integrated information technology to streamline the processes. Regular PDSA cycles were used in meetings to elicit feedback and address barriers. The results established a referral rate of 40% and an increased enrollment rate of 14% from the previous two months. The findings of this effort can inform current MTPPP hosts and future practices to utilize the PDSA cycle to improve processes. Although the results are affirmative, more time should be dedicated to the quality improvement effort, allowing for more data collection and PDSA cycle completions.

CHAPTER ONE

SUPPORTING CAREGIVERS OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

Introduction

Children and youth with special health care needs (CYSHCN) are a diverse group of children defined as those "who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions" who require health care needs and support services beyond that required by children generally (Maternal Child Health Bureau [MCHB], 2021, para. 2). Nearly 20% of Montana children met this federal definition (Child and Adolescent Health Measurement Initiative, 2019-2020). Supporting CYSHCN holistically and comprehensively has been a heavy challenge for health care providers, state health leaders, and other stakeholders (Association of Maternal and Child Health Programs [AMCHP], 2017). For decades, national workgroups have partnered to develop national standards to ensure a CYSHCN's medical home is comprehensive, coordinated, and family-centered (National Academy for State Health Policy [NASHP], 2020). Despite these efforts and intentions, 54.5% of Montana CYSHCNs' care does not meet the medical home criteria (National Survey of Children's Health [NSCH], 2016). This highlights a tragic reality that the needs and services of CYSHCN continue to be unmet or unrecognized (Kuo & Turchi, 2021).

Significance of Problem

Caregivers are a critical component of ensuring CYSHCN needs are recognized and met, particularly in Montana where access to quality health care is complicated by all 56 counties being considered medically underserved (AMCHP, 2018). The vastness of Montana can make care more fragmented, and resources and services can also be difficult to access. Caregivers rely on the partnerships they have with their child's health care provider to successfully navigate their CYSHCN health care, especially in Montana, where limited care coordination programs exist and the burden of coordination falls on the shoulders of caregivers. Sadly, only 52% of caregivers report "doctors always spend enough time with them" (NSCH, 2016) often leaving caregivers feeling unsupported. Lack of time with the medical team can result in the non-medical needs of caregivers and CYSHCN going unnoticed. Rarely do Montana pediatric medical homes include family-centered components aimed at supporting the caregiver beyond the child's medical needs, particularly in care coordination and resource education. Providers also recognize their limitations in supporting caregivers of CYSHCN. One Montana provider reported:

> I recognize our practice can do a better job supporting our special needs caregivers. I can physically see the heaviness on their faces. They're tired. Sometimes I don't know what to say to them to make it easier. I hear all the time how limited resources we have in our state and how confusing our healthcare system is to parents. I know there are resources out there to support them, I just don't have the bandwidth to keep up with them (Anonymous Montana Provider, personal communication 2021).

Being a caregiver and promoting the health of CYSHCN requires meticulous attention and time that can be complex, overwhelming, stressful, and burdensome (Caicedo, 2014; Carnevale et al., 2006). Caregiver burden is a multidimensional concept that has been broadly defined as "the physical, emotional, and financial toll of providing care" (Pilapil et al., 2017, p.

191). Caregivers are at risk for caregiver syndrome defined as “a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent” (Catalano et al., 2017, p. 2). Psychological and physical health of caregivers are strongly influenced by caregiving demands (Raina et al., 2005). This stress, burden, and social isolation is a powerful predictor of poor health outcomes for both caregivers, and their children (Evans & Fisher, 2021).

It is well documented that caregivers of CYSHCN are at increased risk of having family and emotional distress, disproportionate time constraints (Daire et al., 2011), social challenges, poor social support, decreased resource engagement, and difficulty accessing appropriate, comprehensive, and coordinated health care (Abdi et al., 2020). Caregivers have a lower self-reported health-related quality of life and have more than twice the odds of reporting chronic conditions and activity limitations as well as greater odds of reporting poorer general health than caregivers of healthy children (Pilapil et al., 2017). Additionally, caregivers report their health as fair or poor twice as much as the general population, and one-in-four believe caregiving directly has made their health worse (Nelson & Yadrich, 2013). Caregivers have higher levels of depressive symptoms, mental health problems, and psychiatric disorders and are nearly twice as likely to report using mental health services (Pilapil et al., 2017). Caregivers reported feelings of frustration, anxiety, and anger. They feel isolated, helpless, and hopeless. They also have difficulty remembering and focusing on tasks (Caicedo, 2014).

Emotional strain from the physical and psychological dependency of CYSHCN, while also feeling unsupported by the medical team to navigate a highly fragmented and commonly unsupportive health care system, can have serious implications for the caregiver and CYSHCN (Carnevale et al., 2006). Providers need to have an awareness of the poor outcomes’ caregiving

can create because unmet caregiver needs pose a significant risk to the psychological, physical, and social well-being of not just the caregiver but also the child (Daire et al., 2011). Caregiver well-being directly influences the adaptive functioning of the family and the child's well-being, and it is imperative to review and understand the dynamics of caregiver quality of life (Catalano et al., 2018; Hatzmann et al., 2008). Not only does caregiver burden impact the overall well-being of the caregiver, but high levels of caregiver burden can also negatively impact the quality of ongoing care for CYSHCN (Pilapil et al., 2017; Carmassi et al., 2021; Wu et al., 2020). DePasquale (2020) found caregiver state of mind has a direct impact on the development and well-being of a child, and caregiver-child synchrony directly impacts children's long-term development. Therefore, it is imperative for medical providers and caregivers to partner within the medical home to build caregiver resiliency in efforts to create a functional, healthy caregiver-child synchrony that ultimately promotes the best outcomes for a CYSHCN (Abdi et al., 2020).

Supporting caregivers of CYSHCN requires a thoughtful approach. Caregivers often report they feel as if health professionals and medical teams do not understand their family situation. A caregivers' lived worries, physical impacts, and financial strains encompass a journey unique to the family and are often experiences a provider and medical team are unable to relate to. Caregivers frequently report difficulty talking with physicians and nurses and report feelings that people do not understand their family situation (Sepulveda et al., 2020). Despite considerable evidence and understanding of caregiver needs, too many caregivers of CYSHCN feel they do not receive adequate levels of support in their medical team (Abdi et al., 2020). A Montana caregiver of a youth with a special health care need reflects the following:

> Where do I begin? Between the ventilator alarms, tube feedings, diaper changes, and her overall crappy sleeping schedule, I have averaged 5.5 hours of sleep per

> night this week. And this is her healthy. She was supposed to have seven medical appointments last month, and I ended up canceling half of them because we just got overwhelmed. I feel, well I know, her health relies on my ability to function and know everything, and I constantly feel like her doctor just does not get how dangerous that is. "Make sure you're taking care of you and asking for help" ... uh, okay…Thanks doc. Sure. Easy for him, but 1) how do I truly do that, and 2) where do I find this help? I'm just tired and lonely … sometimes I'm just hopeless (Anonymous Montana Parent, personal communication, 2021).

Purpose

Having a support system is one of the main factors predicting caregiver health-related quality of life (Hatzmann et al., 2008), and having a support system comprised of people who have had similar experiences is crucial. One caregiver explains, "You know people often want to fix your problem and it's all in good faith that they do it, but sometimes they don't understand that some things are not fixable… And people who are in that situation seem to understand that and just allow you to be. And that's a good thing, I like that." (Hartzmann et al., 2008, p. 778).

Peer-to-peer (P2P) support is defined as frequent, ongoing, accessible, and flexible support that complements and enhances other health care services by creating the emotional, social, and practical assistance necessary for managing the disease and staying healthy" (Peers for Progress, 2020). Peer support offers hope, guidance, information advocacy, and camaraderie in a variety of different settings (Substance Abuse and Mental Health Services [SAMHSA], n.d.) and is essential for physical and mental health and well-being (Hammarberg et al., 2014; Wood, 2016). Caregivers require peer support to share and cope with life experiences, which can simultaneously provide individuals with practical information and social-emotional support (Saxena et al., 2020). Wynter et al. (2015) explain that "the opportunity to talk to other people who have similar life circumstances can reduce social isolation, increase self-acceptance, self-

confidence, self-efficacy, and sense of personal worth and assist parents to feel more competent in managing everyday problems" (p. 70).

P2P support is a creative strategy for reaching groups that health services too often fail to engage, such as caregivers of CYSHCN (Skol & Fisher, 2016). P2P support allows for an unrelenting focus on the caregiver while other team members can focus on the child (Donnelly et al., 2017). Providers of CYSHCN should strategize how they can offer a quality P2P support opportunity for their patients' caregivers and aim interventions at empowering caregivers to engage in an adequate support system to derive emotional support and share the care for their children (Hatzmann et al. 2008). P2P support is essential for caregivers and has several social returns on investment, including a mutually beneficial nature of parent/professional partnership; a future for families where they do not need to rely so heavily on formal systems; an increased connectedness to community resources; and, natural supports, and overall system transformation that is persistent, enduring, and even lifelong (Donnelly et al., 2017). Additionally, there is increasing evidence that supporting the caregiver leads to reducing child symptoms and improving child functioning (Donnelly et al., n.d.).

CHAPTER TWO

REVIEW OF LITERATURE

Introduction

Specific areas of the literature related to the purpose of this project include the impact of P2P support as an intervention on caregiver outcomes. With the assistance from the Montana State University librarians, a literature review was completed using CINAHL Complete, Cat Search, PsychINFO, and PubMed. The following search terms were used: “caregiv*,” “peer support,” “social support,” “disabilit*,” “parent support,” “health outcome*,” “peer-to-peer,” “special need*,” “Children and youth with special health care needs,” and “parent carer.” The results were limited to academic journals and full-text articles, published in English and peer-reviewed. The author’s initial search criteria aimed to limit articles published between the years 2014–2021. Due to the limitation of quality published studies, articles were accepted between the years 2005–2021.

The Impact on Caregivers

Effective peer support is important for the promotion of overall well-being in the caregivers of CYSHCN (Dodds et al., 2018). The positive outcomes found in the literature associated with P2P support are vast. Mowbray et al. (2021) underwent a systematic review of psychological-based outcomes in peer support services and identified 84 outcome measures that P2P support positively impacted. Reducing isolation, improving psychological well-being, and increasing knowledge are a few common findings (Mowbray et al., 2021). Catalano et al. (2018)

underwent a systematic review of 23 quantitative and qualitative studies and identified three broad themes that emerged when caregivers participated in P2P support: the importance of social support by other caregivers, the effectiveness of training parents in stress management strategies and developing problem-solving skills, and the importance of providing caregivers with relevant and accurate information and resources about a child's condition. Sokol and Fisher (2016) conducted a systematic review of 47 studies assessing the reach and effectiveness of peer support. The authors found that 93% of studies reported significant differences or changes favoring peer support.

Social and Emotional Support

The isolation that parents report as caregivers of CYSHCN can be devastating. P2P support programs have been shown to help address the significant social and emotional distress of caregivers of CYSHCN (SAMSHA, n.d.). P2P support programs reduce feelings of isolation and loneliness (Evans et al., 2020; Treadgold et al., 2021) that are so prevalent among caregivers. A caregiver of one P2P program reported, "Being the parent of a special needs kid is very isolating and going to My Time you feel that you're the normal one for a while" (Hammarberg et al., 2014, p.778). There is clear evidence that participation in a P2P program provides a sense of belonging (Hammarberg et al., 2014; Mills et al., 2021) that ultimately decreases feelings of isolation and loneliness, peace, energy, and joy (Evans et al., 2020).

In addition, there have been clear reductions in parent stress for P2P participants (Hammarberg et al., 2014; Jamison et al., 2021; Evans et al., 2020). Treadgold et al. (2021) found that caregivers who participated in P2P support reported improved comfort, decreased feelings of sorrow, and increased feelings of reassurance and validation in their journey.

Jaminson et al. (2017) found caregivers reported decreased stress when interacting with P2P support, which resulted in significant improvement in levels of caregiver strain.

Problem Solving and Education

P2P support can be used across health care systems to promote the utilization of services and to address disparities in access to care (Jamison et al., 2021). P2P support has been found to increase knowledge of diseases (Jamison et al., 2021; Peers for Progress, n.d.), improve self-efficacy (Mills et al., 2021; Peers for Progress, n.d.), and improve self-care skills (Peers for Progress, n.d.). The need for parental support is particularly apparent early after diagnosis of a condition. P2P support improves perceived caregiver strain, improves feelings of lack of control, decreases feelings of ineffectiveness, and improves a caregiver's ability to manage strain (Jamison et al., 2021). Mills et al. (2021) found P2P improved awareness of resources and increased participation in and utilization of resources. Participating in peer support also helps caregivers learn how to navigate funding opportunities and deal with the day-to-day challenge of caring for a CYSHCN (Hammerberg et al., 2014).

In a quality improvement effort at a clinical practice location in Rhode Island, the medical team aimed to improve short- and long-term health outcomes for CYSHCN and their families within a medical home and created the Pediatric Enhancement Project. This project placed a trained peer resource specialist in a clinical setting who aimed to link families with community resources, assist physicians and families in accessing specialty services, and identify system barriers to coordinated care. This program successfully demonstrated utilizing P2P support reinforced health care messages, provided patient education, and helped aid in care coordination (Heron et al., 2015). Staff at this clinical practice provided feedback that P2P

support brought a culture change to the organization that brought “huge” value and peer resource specialists were “invaluable” (Heron et al., 2015, slide 22).

Almost universally, caregivers interfacing with P2P support report positive aspects of being involved in P2P support. However, it was identified in the literature that some caregivers did not find P2P support helpful or a positive experience (Hammerberg et al., 2014; Treadgold et al., 2020). Hammarberg et al. (2014) identified a few social and emotional reasons for discontinuing support participation, including having overwhelming emotions during participation, generally not feeling supported, no longer needing the support, and lack of cohesiveness within the P2P support environment.

Perspective of Peer-to-Peer Support Providers

Munson et al. (2009) interviewed 16 parent advocates providing P2P support who described their role as caregiver advocates and supports as distinct and invaluable. They explained that they offered services most providers could not provide within the clinical setting and had flexible roles that allowed them to address the unique needs of caregivers, which expanded traditional supports and services that ultimately blended informal supports with formal services. They also helped families translate content and provide links to other resources, navigate the child’s health care journey, and empower caregivers (Munson et al., 2009).

Barriers to Accessing Peer-to-Peer Support

To honor a family-centered approach, medical providers and their teams must work to develop strategies to promote caregiver support, connectedness, and resilience. Although pediatric medical offices are perfectly positioned to support caregivers and integrate P2P

interventions, providers, and facilities often do not have the capacity to manage the intricacies of a P2P support program, nor do they have the extra funding to provide additional services without proper reimbursement. In addition, finding caregivers willing and able to provide mentorship and support is a challenge (B. Thompson, personal communication, November 2, 2021). The director of the Montana Parent Partner Program (MTPPP) writes:

> One thing I know is that the reason I want to use caregivers in our program, is also the greatest limitation and cause for turnover. They're parents of children with special needs! Their child's situation and their experience with it gives them experience and credibility, but it is also the thing most likely to take them out of service for a significant period or lead them to need to quit altogether. Seven of the nine PPs that have left their positions did so for that reason. (Personal communication, 2022).

In addition, having such diversity in evidence and a lack of objective measures of impact are major challenges in disseminating and standardizing programs (Evans et al., 2020). Without standardization and evaluation, system-level opportunities may be minimal. Without convincing data, programs are at risk of losing support from necessary stakeholders and funders.

The Montana Parent Partner Program

Montana's vastness contributes to the very limited opportunity for quality P2P support. However, Children's Special Health Services (CSHS), a program within the Montana DPHHS, funds and promotes an evidence-informed P2P mentorship program, the MTPPP. Like the Pediatric Enhancement Project, this program aims to offer every Montana caregiver of a CYSHCN access to a relationship with a peer for "inspiring and encouraging hope by providing access to relationships, information and resources" (CSHS, n.d). The vision and purpose statement are listed in Appendix E. The MTPPP offers an opportunity for caregivers to connect

with a personally experienced caregiver, a Parent Partner, who is professionally trained to listen and strategically use their own story in a way that is healing and informative to the caregiver they are supporting. A Parent Partner understands the burdens by virtue of shared experience and is trained to help a caregiver navigate their child's health care journey. A Parent Partner's role is to collaborate with a medical team and address the non-medical needs of a family, thus allowing the medical staff to work at the top of their license, while also supporting caregivers in ways that only experienced caregivers of CYSHCN understand. An MTPPP logic model is included in Appendix D. Any clinical setting that interacts with CYSHCN regularly can apply to have the MTPPP in their clinic. The program is of no cost to the clinic, and each Parent Partner is paid through funding provided by the CSHS.

Although the MTPPP is readily available to any Montana provider and caregiver, there are barriers to caregivers accessing the program. Of the estimated 43,500 CYSHCN in Montana, only three clinics currently offer the MTPPP to their caregivers of CYSHCN. The director of the MTPPP reports only 311 families in Montana were served in 2019–2020 (personal communication, September 22, 2021).

A practice site manager at a Montana clinic location hosting the MTPPP explains that their team aims to offer every caregiver access to the MTPPP. However, there are several demands on the provider, and remembering to refer families in a 15-minute clinic appointment is a barrier; "we already ask our providers to remember to discuss and assess a million things. Adding one more thing for them to address is a big ask" (D. Zimmerman, personal communication, November 11, 2021).

CHAPTER THREE

METHODOLOGY

Introduction

The DPHHS, the practice site location (PSL), and this author aspired to ultimately expand caregiver social support, decrease caregiver stress, and improve access, knowledge, and utilization of resources by partnering and crafting a quality improvement effort that would improve caregiver access to a quality, evidence-informed P2P support program: The MTPPP. Due to the time constraints of this project, efforts were directed toward educating the providers of the PSL on the importance of quality evidence-informed P2P support and improving the workflow, referral, consent and enrollment process. The development of this quality improvement (QI) project was guided by the PDSA Quality Improvement Framework.

Agency Description

This PSL provides care to approximately 800–1000 children, youth, and their caregivers each year (Dr. A. Elias, personal communication, September 22, 2021), nearly all of which meet the federal definition of a CYSHCN. The PSL participating in the quality improvement effort has housed the MTPPP since May 2018. At the time of the QI project, the clinical team that interfaced with the program included one medical director, one medical geneticist, one nurse practitioner, two genetic counselors, a registered nurse, a Parent Partner, and three administrative assistants/schedulers.

PDSA Cycle Tool

Historically, the PSL relied primarily on paper tools and memory to provide resources to their patients, making sustained improvement challenging. To support quick and sustainable change, this author guided the QI project by utilizing the Institute for Healthcare Improvement's model for improvement and the Plan-Do-Study-Act (PDSA) cycle tool to support continuous improvement. The PDSA cycle is a commonly used improvement process in health care settings (Varkey et al., 2006) and allowed for a "trial and learning" approach so a suggested solution could be proposed then tested and carried out on a small scale before any changes are made to the whole system (Varkey et al., 2006).

Ethical Considerations

An exempt application for this QI project was submitted to the Montana State University Institutional Review Board (IRB) (See Appendix F). No patient identifiers were used or collected during the data collection procedures. Because the study population was the staff and medical providers of the PSL, written consent from caregivers was not required for this project.

Project Implementation

The first step in the QI project was to identify stakeholders and gather information about the culture of providing P2P support for caregivers of CYSHCN in Montana and build a QI team. Interviews were completed with the PSL, caregivers of CYSHCN, CSHS, the MTPPP, and researchers representing Peers for Progress. Each stakeholder was asked if additional members should be engaged in efforts to create a holistic stakeholder group. The final QI team comprised

of the chief administrative officer, medical geneticist, nurse practitioner, two genetic counselors, the Parent Partner, EHR (electronic health records) staff, administrative assistants/schedulers, CSHS staff, and the MTPPP director. Stakeholders, stakeholder category, stakeholder perspective, and role in the project are outlined in Appendix B.

Because the group was so large, and it was not necessary for every member to be at each meeting, a Core QI team was developed consisting of the clinical team (nurse practitioners, genetic counselors, the Parent Partner, and administrative assistants/schedulers). Each member fell within different areas of expertise, which are organized below within the roles defined by the IHI (2020):

- Clinical Leader: Medical geneticist and chief administrative officer. These members had authority in the practice location to test and implement the proposed changes. Both members understood the clinical implications and consequences of the proposed change and how those changes could trigger change in other parts of the system.
- Technical Expertise: Program director of the MTPPP, CSHS program staff, and Peers for Progress researchers. These members offered technical assistance and provided guidance on improving the system of care for CYSCHN and their caregivers.
- Other members: EHR staff, nurse practitioners, genetic counselors, dietician, administrative assistants/schedulers, and the Parent Partner. These members knew the challenges of the system intimately.
- Day-to-Day Leadership: The author. The author was the day-to-day leader of the project who understood the details of the system and the various effects of making changes within the system the team aimed to improve.

- Project Sponsor: Chief administrative officer. This member had executive authority to provide liaisons with other areas of the organization and served as a link to senior management and the strategic aims of the practice location. This person was not a day-to-day participant in the project.

Resources

Although this QI effort did not require additional monetary funding, it did require additional staff time outside of their typical role and access to the EHR (EPIC). Within the timeframe of this QI project, the estimated time of staff included the following:

- Project Leader (author): 270 hours dedicated to the research, development, training, team check-ins, and oversight of the QI program. A cost to the practice location.
- Administrative Assistants/Schedulers: Approximately 25 hours dedicated to brainstorming, drafting, and testing the new workflow process, team check-ins, collecting data, and receiving education/training. A cost to the practice location.
- Providers (Genetic Counselors, Nurse Practitioners, Medical Geneticists): Five hours dedicated to testing the new workflow process, team check-ins, and receiving education/training. A cost to the practice location.
- EHR/Informatics: Approximately five hours dedicated to an initial team check-in and logistics of gaining EHR access for the Parent Partner. A cost to the practice location.
- Parent Partner: Approximately five hours dedicated to testing the new workflow process, team check-ins, and receiving education/training. A cost to CSHS.

- CSHS: Approximately five hours dedicated to interviews, providing technical assistance, providing data, and an attending an initial team check-in.
- MTPPP Leadership: Approximately five hours dedicated to interviews, providing technical assistance, and attending an initial team check-in.

Practice Site Location Feedback and Identified Barriers

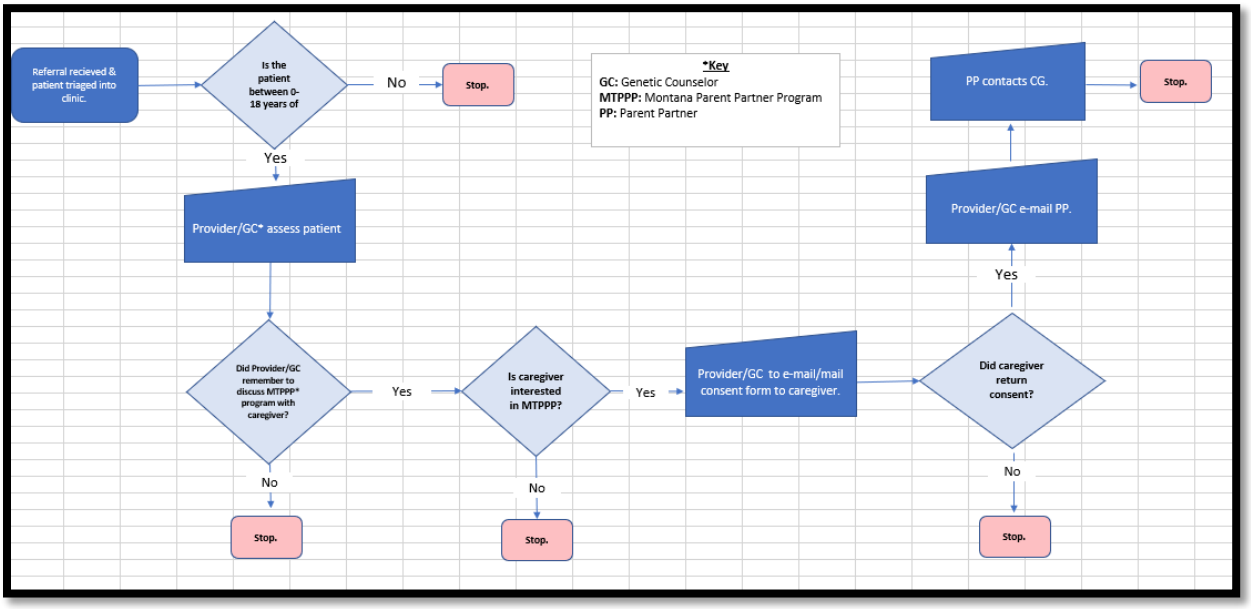
In September and early November 2021, two one-hour meetings were held with the Core QI team to elicit feedback on how the PSL supported caregivers of CYSHCN. One salient theme during these meetings was the desire and commitment of the team members to improve access to P2P support for caregivers of CYSHCN. During each meeting, participants were encouraged to discuss the challenges of utilizing the program. Participants were asked to identify any barriers that existed with referring caregivers to the MTPPP and brainstorm opportunities for improvement.

This author initially observed that there was no policy outlining the workflow, referral, consent and enrollment process and there were no formalized expectations between the PSL and the MTPPP. Also, there were no clear metrics defined by the MTPPP, CSHS, or the PSL to define success or monitor progress of the program. The Core QI team identified three additional shortcomings. A point of initial contestation among Core QI team members was the lack of education about the purpose of the MTPPP. Overall, the team felt the MTPPP was beneficial, but they did not feel adequately prepared to explain the purpose of the program to caregivers and had low motivation to refer. The team could not recall a time when they had a formal presentation on the services provided by the MTPPP. Second, the members discussed the lack of a formalized and systematic workflow, referral, consent and enrollment. The Core QI team also reflected that

there were inconsistencies in the processes. There was not a standard of operating procedure outlined for the MTPPP, and the team denied a systematic approach or routine. This led to significant variance in how or if caregivers were referred/enrolled caregivers into the program and the clinical team reported referring to the MTPPP "occasionally" and "intermittently." Additionally, the practice site location's initial Parent Partner resigned at the end of 2020, and the team went approximately eight months without P2P support for caregivers and the Core QI team did not engage in the workflow, referral, consent and enrollment and could not recall many of the processes historically in place.

The former workflow/referral process is highlighted in Table 1. Briefly, caregivers who had CYSHCN up to the age of 21 years qualified for the MTPPP. Providers assessed the patient/caregiver's psychosocial situation and determined whether the caregiver was a good candidate for MTPPP. This determination was based on the providers' opinion or if the caregivers requested help or inquired about the program. The MTPPP consent form (Appendix E) was required before the MTPPP could contact a caregiver and be sent to every caregiver being considered for the program. Providers would have the caregivers sign the consent form at the appointment if they remembered, or they would email or mail the MTPPP consent form to caregivers after the appointment. If consent was returned, providers would email the signed consent form to the Parent Partner, which acted as the notification for the referral. The Parent Partner would then reach out to the caregiver. The Parent Partners communication with the caregiver was not documented in the patients health record and the providers were not notified if the caregiver was contacted.

Table 1. Former Workflow and Referral Process



Finally, the Core QI team identified the poor return rate of consent forms. For a caregiver to participate in the MTPPP, they must sign a consent form permitting the PSL to release their personal information to the Parent Partner. If the consent is not signed and returned by the caregiver, the MTPPP cannot be notified of the referral and the caregiver cannot be enrolled in the program. Prior to the start of the QI project, consent forms were signed at the time of visit or sent to caregivers via email or mail. If not signed at the visit, the families would be required to print off the consent form, re-upload the form, and email the form back, or they would have to mail the forms to the PSL. Unfortunately, the number of consents sent to caregivers (referral rate) compared to the number of consents returned (the enrollment rate) was not documented historically. In this clinical setting, there is no objective data to support the signed consent return rate is low. However, the signed consent return rate has been a concern of the MTPPP across the program, and the Core QI team agreed it would be a reasonable area to focus improvement efforts and to establish a baseline to track for further improvement opportunities.

SMART Goals

Education

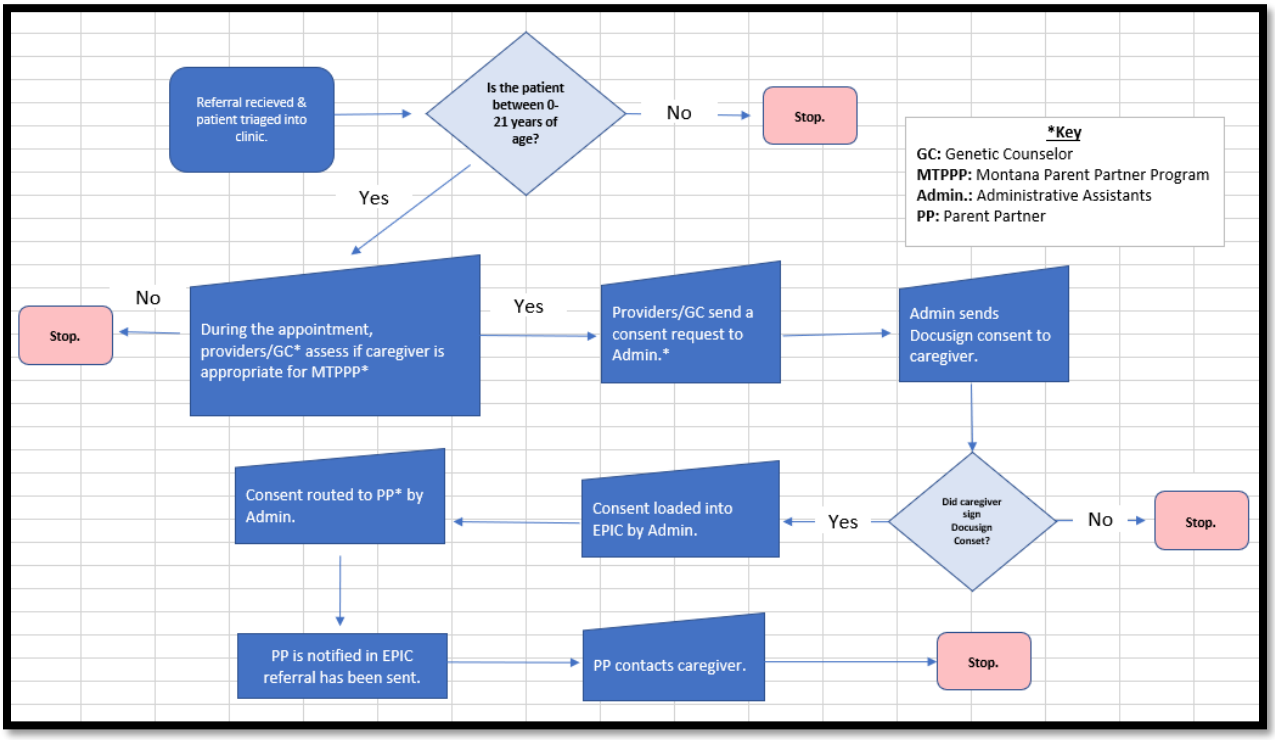
When the new Parent Partner started in May 2021, the PSL had renewed motivation to utilize the MTPPP to offer a functional, evidence-informed P2P support opportunity for every caregiver of CYSHCN in which the practice serves. Before the implementation phase or before work could begin on improving outcomes for caregivers, this author aimed to gain buy-in from the Core QI team by educating the team on the benefits of P2P support and familiarizing the team with the components of the MTPPP model and proposed a QI implementation plan. By October 15, 2021, this author aimed to have 100% of the SCHMG clinical team and administrative team commit to participating in this QI project and approve a comprehensive implementation plan. To achieve this, each team member participated in one one-hour education session related to services provided by this author based off material provided by the MTPPP. A question-and-answer session was offered after the presentation to ensure the team had increased confidence in describing the program, and feedback was elicited from each member to ensure the implementation plan would be successful. Each attendee verbalized increased confidence after participating in the presentation, and 100% of the team committed to and approved the implementation plan.

Redefining the Workflow, Referral, and Consent Process

Once the team was educated and expressed increased confidence in the MTPPP program, the Core QI team met to brainstorm ways to improve the new workflow, referral, consent and enrollment process for the program. The new process that the Core QI proposed is highlighted in Table 2. Caregivers' qualifications for the program and the MTPPP consent requirement did not

change. The new process began at the time of patient intake and assessment. Each note that is written after a patient is evaluated is guided by a pre-drafted template that guides the providers' discussion. In this QI effort, a charting header "Montana Parent Partner Program" was added to the social history section of the note. This question would prompt the provider to briefly discuss the program with the caregiver and determine their interest. The provider would type a response such as, "referred" or "not interested at this time" or "currently followed." If a referral was indicated and the caregiver was interested, the provider would create a note after the visit to EPIC (creating an "Encounter") and route a note stating, "Please send caregiver DocuSign consent form to the email on file." to the administrative assistants. A ".dotphrase" (used with commonly used chunks of text that can easily be inserted into a patient note by typing a period [the dot] followed by a short user-generated phrase) was created in an effort to keep the message uniform, quick, and easy. The administrative assistants were automatically notified in EPIC that a message was waiting for their review. The administrative assistants would then send the Montana Parent Partner a consent form via DocuSign to the caregiver. If the caregiver signed the consent form, the administrative assistants would route the consent form to the Parent Partner, which notified the Parent Partner of the new referral. Once the consent was signed, the caregiver was considered "enrolled" into the program.

Table 2. New Workflow/Referral Process



By gaining better knowledge and understanding of the MTPPP and redefining the workflow, referral, consent and enrollment process, the team could consistently provide an opportunity for caregivers of CYSHCN to have access to an expanded caregiver social support network that provided improved access, knowledge, and utilization of resources that had the potential to ultimately lower caregiver stress. The QI team would consider the new process successful if by March 1, 2022 referrals made were 50% of total CYSHCN patients evaluated. The total number of referrals in November 2021 and December 2021 was just one new referral. To get a more expansive summary, the data analyst at the Department of Public Health, on behalf of the MTPPP, ran a report highlighting how many new MTPPP enrollments the PSL completed (Table 3).

Table 3. Enrollments to the MTPPP

Mar-21	**Apr-21**	**May-21**	**Jun-21**	**Jul-21**	**Aug-21**	**Sep-21**	**Oct-21**	**Nov-21**	**Dec-21**
0	0	0	1	4	2	0	2	0	1

Establishing long-term outcome measures is critical to the PSL, MTPPP, and CSHS. Determining which metrics are valuable to the three entities will likely be a continuous QI effort. Although the program is evidence-informed and adopted by CSHS to support the system standards for CYSHCN, the MTPPP has had limited evaluation support, and no formal outcome measures have been identified or agreed upon to measure the success of the program (L. Smith, personal communication, September 20, 2021). However, evaluation recommendations (Appendix C) are available from a CDC/Harvard evaluatio. It is reasonable for the leadership of CSHS and the MTPPP to use the evaluation tools listed in the Harvard/CDC evaluation to evaluate the long-term impact of the MTPPP on caregiver social support, caregiver stress, access, knowledge, and utilization of resources.

CHAPTER FOUR

RESULTS AND DISCUSSION

Introduction

Providing an opportunity for caregivers to have quality P2P support in the clinical setting is crucial in holistically supporting CYSHCN, particularly in a rural state like Montana, where much of the burden of care falls to the caregivers. The PSL dedicated six months, hoping to improve caregiver outcomes by improving access to the MTPPP. The overarching goal of the QI improvement project was aimed at referring 50% of caregivers of those CYSHCN aged 0-21years who were evaluated. Two areas of improvement were proposed by the Core QI team during the implementation period: 1) improve the workflow, referral, consent and enrollment process and 2) utilize the DocuSign tool to improve the number of consents sent back by caregivers so caregivers could be enrolled into the MTPPP. By re-creating the process and integrating the DocuSign tool, the PSL designed a concise, consistent, and reliable process that enhanced the team's ability to be good stewards of the MTPPP.

Timeline of Project Phases

A component model is highlighted in Appendix G, and the detailed timeline is outlined in Appendix H. This project took place between August 2021 and April 2022. The pre-implementation phase was held between August 2021 and December 2021. The implementation phase was held between January 2022 and February 2022. The wrap-up phase was held between March 2022 and April 2022.

Participants

The general target population for this QI effort was health care providers and staff providing care for CYSHCN and their caregivers in a clinical setting. For this project, the participants consisted of one nurse practitioner, two genetic counselors, a registered nurse, and two administrative assistants who worked in a medical genetic clinic.

PDSA Cycles: Redefining the Workflow and Referral Process

When it was time to integrate the new workflow, referral, and consent process, a logical sequence of four repetitive steps (Plan, Do, Study, and Act) (Appendix A) allowed for short, quick tests. Going through the steps guided the clinical teams' thinking process and broke down the goals into steps and then evaluated the outcomes, improved them, and tested them again (Agency for Healthcare Research and Quality [AHRQ], 2021). Each PDSA cycle was designed to be as brief as possible for the team to gain knowledge. Each cycle had a small patient size and was limited to strictly genetics patients. In the days following the clinics, this author met with the providers and administrative staff to elicit feedback from the prior clinic. These meetings were brief and informal. The feedback was elicited from the providers individually and then presented to the group during a larger group meeting to brainstorm any areas of improvement or change.

Feedback from PDSA Cycles

During the first few weeks of the project, the providers reflected on creating an individual patient-specific encounter in EPIC and routing each consent request to the administrative team was time burdensome. Instead, the team suggested sending one email to the administrative team

after each clinic day, which listed all the patients in which the provider was requesting a consent form be sent to the caregiver. At the end of the implementation cycle, the Core QI team reflected that this was much more efficient and easier to track.

It became evident after a few clinic days that the administrative team was not monitoring which caregivers were sent a consent form. Although it was relatively simple to go back and filter through the data, it was inefficient and an opportunity to solidify process measures. As a response, the Core QI team developed an MTPPP Referral Tracking sheet (Table 4) to assist in keeping accurate track of which patients returned the consent forms. This sheet was strictly used by the SCHMG staff. Clinic data and patient names were not collected, and only the totals were included in the data for this project.

Table 4. MTPPP Referral and Enrollment Tracking Form

Month						
	Clinic Date	Patient Name	Requests Sent (From Provider to Admin)	DocuSign Sent (From Admin to Caregiver)	DocuSign Signed (By Caregiver)	Referral Made (From Admin to MTPPP)
Totals			0	0	0	0

Process Goals

The first process goal the QI team established between January 1, 2022 and February 28, 2022 was for 100% of providers to send a request via EPIC to the administrative assistants and request the MTPPP consent form be sent to caregivers who have been identified as good candidates for the MTPPP after the CYSHCN's appointment. This goal was initially made to ensure every provider was actively identifying caregivers the MTPPP could serve, and they were participating in a standardized process to support consistency. This goal was met but modify to in the context of e-mail and all four of the health care providers at the PSL engaged caregivers in

a discussion about the MTPPP and sent a total of 20 requests via EPIC to the administrative assistants requesting a consent form be sent to the respective caregivers (the metric is defined as a “referral”).

The administrative team transformed the MTPPP paper consent form into a DocuSign form, which allowed caregivers to virtually sign the consent form directly from their email. Subsequently, the QI team’s second process goal was to have 100% of caregivers who were identified as good candidates for the MTPPP be sent a consent form via DocuSign between January 1, 2022 and February 28, 2022. This goal was met, and all 20 caregivers were sent a consent form via DocuSign. This result shows the team consistently followed the new workflow and referral process.

The final process goal the Core QI team set was for 100% of caregivers who returned the consent form to be enrolled into the MTPPP and the Parent Partner would be notified of the signed consent via EPIC. This goal was also met, and the seven caregivers who returned the consent form were enrolled to the MTPPP and the Parent Partner was notified. This was another promising result that the new workflow and referral process was being followed.

Outcomes

In November and December 2021, it is unknown how many caregivers providers requested by sent a consent form. However, data shows only two caregivers were enrolled into the program out of the 66 patients evaluated aged 0–21 years: a total enrollment rate of 3%. Note: The team recognizes there is likely more than one caregiver involved in the CYSHCN care. For this project and data collection, each CYSHCN will be associated with just one caregiver.

During the implementation period in January and February 2022, 50 CYSHCNs were evaluated. Table 5 highlights the data collected during the two-month implementation phase. Unfortunately, a data metric was not created to distinguish whether providers discussed the MTPPP with each of the 50 CYSHCN caregivers. Although every caregiver of the pediatric patients evaluated during the implementation time frame was considered eligible, it should not be assumed that every caregiver had the MTPPP discussed/offered.

Out of the 50 CYSHCN evaluated, the providers requested consent forms be sent to 20 caregivers of CYSHCN; a 40% referral rate. This did not meet the Core QI team's goal of a 50% referral rate. However, this metric does not truly illustrate the marked improvement the PSL accomplished. Although there is no historical data for comparison, the team reflected discussing the MTPPP with at least 40% of caregivers and a referral rate of 40% within the given timeframe was a marked improvement and showed significant progress in how often caregivers were engaged in discussion about the MTPPP. Of the 50 pediatric patients evaluated within the timeframe, seven were enrolled into the MTPPP and ultimately served by the program; an overall enrollment rate of 14% and a 11% improvement from the two months prior.

Table 5. Data Collection Table

Clinic Date	Total Pediatric Patients	Requests Sent (From Provider to Admin)	DocuSign Sent (From Admin to Caregiver)	DocuSign Signed (By Caregiver)	Referral Made (From Admin to MTPPP)
January 5th	5	0	0	0	0
January 6th	3	3	3	0	0
January 18th	2	0	0	0	0
January 19th	5	0	0	0	0
January 20th	1	0	0	0	0
January 26th	5	2	2	0	0
February 2nd	4	2	2	0	0
February 3rd	5	2	2	2	2
February 8th	3	1	1	0	0
February 15th	3	0	0	0	0
February 16th	2	0	0	0	0
February 17th	4	2	2	2	2
February 22nd	4	4	4	2	2
February 23rd	4	4	4	1	1
Totals	50	20	20	7	7

Of the 20 caregivers who expressed interest in the program and were sent a consent form, only seven returned the consent form and were subsequently referred to the MTPPP: a consent return rate of 35%. Again, this is not a metric the team can compare to historical data. However, the integration of DocuSign appears to have helped improve the return rate of consents since seven referrals into the MTPPP within the implementation period is more than the combined five referrals between August and December 2021. This data point sets a foundation for future growth and improvement.

Barriers, Challenges, and Lessons Learned

During the implementation phase, it was quickly learned that the typical chaotic clinical setting schedule can often complicate the momentum of a QI effort, and this project and setting were no exception. It was a challenge to connect with each provider immediately after the clinical day, and often did not happen until days after. Although flexibility is an important

component of an improvement effort, this likely impacted the quality of feedback. Moving forward, for long-term sustainability, the team will schedule 15 minutes during the first team meeting of the month dedicated to MTPPP updates and to discuss any challenges within the program and opportunities for improvement.

Throughout the QI project, there was no policy in place. Arguably, this should have been the Core QI team's first action item after engaging the team in the quality improvement effort. The importance of defining the process and expectations between the PSL and the MTPPP cannot be understated to ensure compliance and expectations. However, the Core QI team has committed to developing either a policy or a standard of operating practice (SOP) that reflects the results of this quality improvement effort.

Although not a concern during the timeframe of this QI project, additional barriers for other clinical settings to consider include lack of EHR access for the Parent Partner, sustainability of funding for the MTPPP (dependent on CSHS federal funding), MTPPP employee turnover of MTPPP, lack of commitment of team members to the project over time, and lack of time to adequately assess, implement, and improve the project.

Lessons learned during the timeframe of this project included the following:

1) Engage collaborators to identify and recommend other stakeholders in an effort to expand the impact of the QI project.
2) QI projects are dynamic and require consistent PDSA cycles and frequent check-ins.
3) Dedicating time to assessing the needs of the project and encouraging open communication between all stakeholders allows for exponential impact on the progression of the project.

4) Change occurs in small steps and not always in a linear way. Because the QI team's dedication to improving health outcomes for CYSHCN and their caregivers remained at the forefront of the project, patience and teamwork were preserved during times of uncertainty or challenge.
5) The goals and expectations of the team should be revisited at regular intervals in an effort to maintain collective accountability.

Discussion

The data collected for this project highlighted a limited story. The data results are optimistic and provide a foundation for future growth and improvement. The interventions the Core QI team implemented and continuously improved had a positive impact on improving access to P2P support for caregivers of CYSHCN. However, the limited timeframe of the project did not allow the team to measure the impact of MTPPP on caregiver outcomes, which will be a critical next step. The stakeholders of this QI effort recognized the value of creating a low-effort intervention to safeguard sustainability. Improving referrals to the MTPPP will set the foundation for future QI efforts and evaluations.

Ultimately, this QI effort increased caregiver access to P2P support by increasing referrals and enrollments into the MTPPP by offering provider education on the MTPPP, improving the workflow, referral, consent and enrollment process into the MTPPP, and making the consent process easier for caregivers to complete to participate in the MTPPP. This improvement provided an opportunity for caregivers to have access to a service aimed at reducing caregiver isolation, improving psychological well-being, and increasing caregiver knowledge of resources in their community.

Recommendations for Health Care Clinics and Professionals

An opportunity to provide an evidence-informed P2P opportunity for caregivers of CYSHCN in a clinical setting is key to meeting the national standards for this population. The first step is seeking out a quality program. In Montana, the MTPPP is vetted by the DPHHS and is available to any clinical setting that frequently serves CYSHCN and its caregivers, at no cost to the clinic. The program can only be impactful if caregivers are referred. It is of critical importance to educate the health care team and develop an effective workflow, referral, and consent process while continuously seeking feedback to ensure the program is being utilized to its fullest potential.

CHAPTER FIVE

MEETING THE DNP ESSENTIALS

Introduction

Earning a terminal degree in nursing was motivated by my determination to better serve the population I will serve in the future. Throughout this education journey, I have prepared for the highest level of leadership in practice and scientific inquiry aimed to better provide and advocate for health care that is safe, effective, client-centered, timely, efficient, and equitable (AACN, 2006). *The Essentials of Doctoral Education for Advanced Nursing Practice* competencies developed by the American Association of Colleges of Nursing (AACN) Taskforce guided and shaped my DNP education, scholarly project, and practice immersion experience through eight foundational outcomes competencies. As I near the completion of my degree, I have completed activities under each essential. This reflection provides a self-assessment of how five of those essentials have been met.

Essential I: Scientific Underpinnings for Practice

This competency is aimed to advance a nurse's scientific foundation (American Association of Colleges of Nursing [AACN], 2006). Throughout my graduate-level coursework, I have improved my scientific foundation by integrating knowledge gleaned from natural and social sciences, ethics, biophysical, psychosocial, analytical, and organizational sciences. At the end of these four years, and after hundreds of hours of researching and filtering through literature and participating in a variety of different clinical settings with different populations and cultures,

I have refined my skills and have incredible confidence interpreting sciences and evidence to develop a holistic care plan that is unique to each patient. Utilizing leadership frameworks, change models, and theoretical frameworks has supported the development of my own personal nursing philosophy, and I now consider myself a champion of evidence-based practices and feel prepared to address current and future practice issues.

Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking

In efforts to improve patient and health care outcomes, organizational, and systems leadership is critical for DNP graduates (AACN, 2006). Meeting this essential was evident during my DNP scholarly project. Throughout the scholarly project, I used organizational theory to collaborate with other health care professionals to achieve optimum outcomes and promote ongoing improvement in a clinical setting. With the skills learned, I led a team through implementing an intervention and evaluating the relevant project outcomes to serve an at-risk population. At the end of the project, I was able to summarize these efforts, successfully defend the project, and disseminate the findings to the relevant agency stakeholders in a way that was replicable and measurable.

Throughout my scholarly project, I utilized my advanced skills to review the literature and delivery models that were feasible within the time frame of my project. I aimed to understand how the PSL's routine and procedures were meeting the system standards of CYSHCN and their caregivers. I became proficient in quality improvement strategies, such as the Plan-Do-Study-Act framework, as well as creating and sustaining changes while also considering organizational and professional culture and financial structures. Ultimately, I was

able to ensure accountability for quality health care in CYSHCN by using advanced communication skills and processes to lead a QI project while also demonstrating sensitivity to diverse organizational cultures and populations, including both the patient and the staff at the PSL.

Essential III: Clinical Scholarship and Analytical Methods for Evidence-Based Practice

My DNP education has prepared me with analytical methods to filter through scientific evidence. Courses in inferential statistics, quality improvement, and evidence-based practice prepared me to meet this essential. Throughout my education, I read hundreds of research articles that require a high-level review for quality. For the scholarly project, I tracked these quality articles in an evidence and synthesis table to track the information for continuous reflection throughout the scholarly project. This led to a quality intervention translated from quality evidence that addressed a practice problem and ultimately promoted safe, timely, effective, efficient, equitable, and patient-centered care (AACN, 2006).

During my scholarly project, I led a team to design, direct, and evaluate an evidenced-based intervention to improve P2P support for caregivers of CYSHCN. During the project, the QI team completed multiple PDSA cycles to collect appropriate and accurate data that would generate evidence for the practice site location and their stakeholders to improve access to P2P support for caregivers.

Essential IV Information Systems/Technology for the Improvement and Transformation of Health Care

The AACN requires DNP-prepared advanced practice nurses to be proficient in the use of information technology and systems (2006). As a DNP graduate, I have learned how to successfully integrate information systems and technology in health care systems and patient care settings. This competency was most evident during my scholarly project and in clinical settings. Within the timeframe of the project, information technology was the frontline in the improvement efforts that were proposed, specifically streamlining the workflow, referral, and consent process. Although I had minimal influence on what information technology was utilized in the clinical setting during my clinicals, I experienced first-hand how important technology is to improve patient outcomes by way of electronic health records, personal health records, electronic prescribing, privacy, and security, health care eLearning, and mobile education/resource applications.

Essential VI: Interprofessional Collaboration

As advanced practice nurses, it is critical we collaborate with a multidisciplinary team to improve patient and population health. It takes multiple professions to meet the demands of today's complex health care environment (AACN, 2006). As a DNP graduate, I have been prepared to facilitate and lead interdisciplinary team collaboration to promote patient-centered care through effective communication and collaborative skills. I will be a key stakeholder in improving health care delivery systems. During my scholarly project, I created a multidisciplinary team to explore strategies and interventions to improve P2P support for caregivers of CYSHCN. I collaborated with state-level experts, national-level experts, public

health officials, clinical professionals, administrative staff, researchers, and caregivers of CYSHCN.

Project Impact on Future Career

Prior to this program, I had several experiences participating in and leading quality improvement efforts. Having guidance and mentorship during this process has allowed me to refine the above essentials to ensure I am a leader who promotes quality, sustainable, and impactful interventions. By embracing successes and working through the challenges brought forth during the scholarly project, my confidence in translating research into a clinical setting has significantly improved. I am entering my professional career with several lessons learned that will impact my leadership and practice style moving forward.

I am now an effective change agent who advocates for innovation, inspiration, and engagement that will transform the health care landscape. Perhaps the most valuable lesson I have grown to appreciate is that change and growth are signs of a healthy team. After this experience, I aim to be a seeker of change and innovation. I feel confident to seek out practice problems, utilize nursing and change theory, and collaborate with a multidisciplinary team to bring forth improvement.

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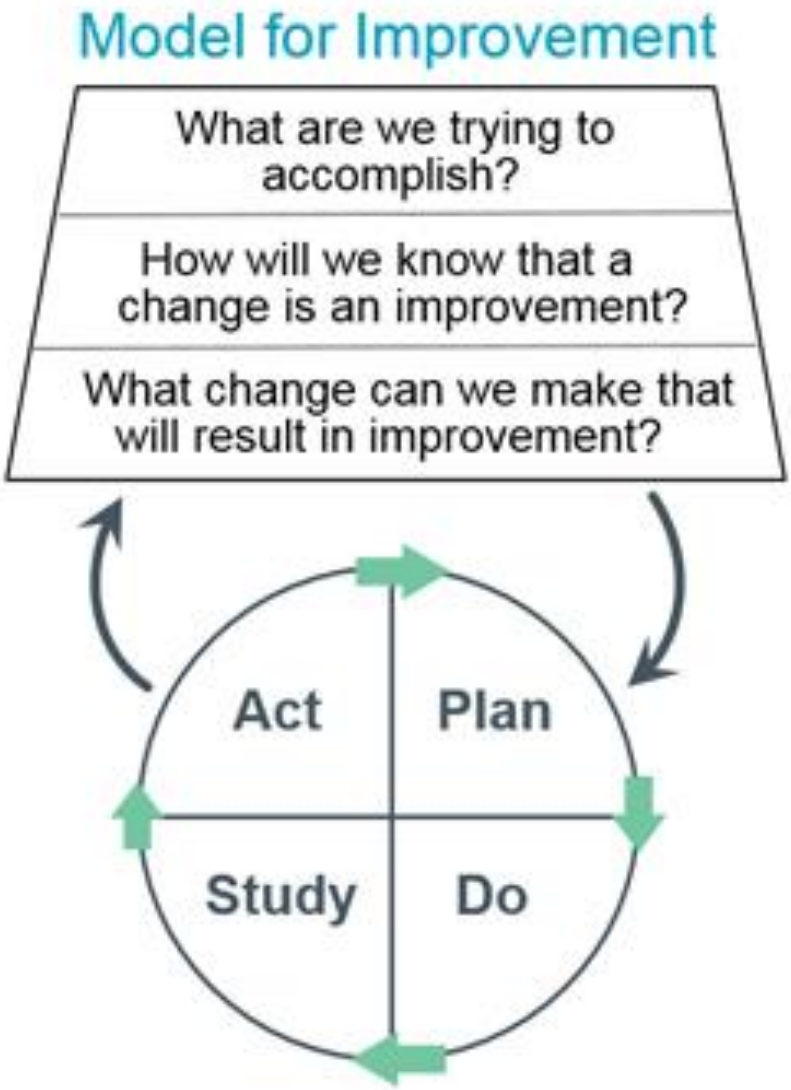
APPENDICES

APPENDIX A

PDSA CYCLE


Model for Improvement
What are we trying to accomplish?
How will we know that a change is an improvement?
What change can we make that will result in improvement?
Act
Plan
Study
Do

APPENDIX B

STAKEHOLDERS

Stakeholder Name	Stakeholder Category	Interest or Perspective	Role in the Project
Children's Special Health Services*	Primary	Cost and program effectiveness	Planning team, review of implementation dynamics, receiving results, interpreting findings, disseminating findings
Montana Parent Partner Program	Primary	Program effectiveness	Planning team, implementation of evaluation and collection of data, receiving results
Practice Leadership	Primary	Program effectiveness	Planning team, implementation of evaluation and collection of data, receiving results

Parent Partner	Secondary	Program effectiveness	Planning team, Receiving results, External reviewer
Providers	Secondary	Cost and program effectiveness	Planning team, receiving results
Administrative Assistants	Secondary	Program effectiveness	Planning team, implementation of evaluation and collection of data

APPENDIX C

HALI PROJECT PURPOSE AND VISION STATEMENT

Hali Project Medical Home Purpose Statement

Our purpose is to produce a system of care that is more effective and efficient, higher levels of satisfaction for both the patient and the provider, and cost savings to our healthcare system.

Our vision

Our vision is providing primary care practices a cost-effective way of providing the patient/family engagement piece of the medical home in a way that improves both patient and provider satisfaction while lowering costs to our healthcare system.

Our mission

Our mission is to help primary care practices identify healthy family/patient partners, then train and support those partners to provide the "non-medical" pieces of the medical home model.

Our Values

Each piece of this project is built on the foundation of these values. While we hope to always be learning new and better ways of doing things, they will always be firmly grounded here.

1. **We are patient centered**. Services and supports should be provided in ways that ensure the patient's needs are being met. Every piece of the system of care should recognize the value of the patient's permanent relationships and consider them as they develop plans of care.

2. **We are family focused**. The patient should always be viewed as part of a family system and treated accordingly. Family members should be engaged in conversation because they have valuable insight information that will enhance just about any plan of care.

3. **We provide individualized support**. We will help produce insight into our families' situations, which will allow the practice to provide higher quality individualized care.

4. **We are culturally competent.** We will build relationships with our families to get to know what is important to them in terms of relationship, customs, and care preferences.

5. **We work at both the individual and system levels.** When we work with families to help them with the things that are important to them, we will certainly uncover things within different systems that need improvement. As we discover those issues, we can work within the community to make those services more accessible.

6. **We are community based.** By hiring partners from within community practices, we can assure families that we will be accessible and knowledgeable about local services and opportunities available to them. We believe this will also allow us to identify local partners who may be willing to support our work in numerous ways.

7. **We build partnerships.** Our philosophy is built around the idea that families have information that only they can bring to the care discussion. That makes it essential to see them as partners in care-giving process if we are going to provide them with the highest quality, individualized care.

8. **We are committed to a strength-based approach.** We believe that dignity is supported when we discover the strengths of a patient and family and allow them to do what they can in those areas. Our job is to encourage them in those things and add support in the areas that are important to them but they cannot do for themselves.

9. **We work to establish relationships with community groups who want to collaborate**. By doing this in communities, we have found that access to those supports has improved. By working together, we believe we can make limited resources go further.

10. **We establish connections to community support organizations.** Finding like-minded local support groups can lessen our dependence on more formal systems and fills gaps where they exist.

11. **Our project is cost effective.** We put this last because at the end if the day, we always have to have a "but what does it cost?" conversation. If a practice is large enough to warrant a full-time partner they can certainly do that. But if a practice is smaller and might only need a partner on a part-time basis, they can arrange appointments in a way that maximizes the partner’s time in the office.

APPENDIX D

MTPPP LOGIC MODEL

Logic Model: Montana Parent Partner Program

Goal: The Parent Partner Program (PPP) provides tailored support and community resources to caregivers and families of CYSHCN, through peer guidance and health system navigation.

Inputs

- Funding
- Parent Partners (PPs) who have CYSHCN
- Clinics, healthcare providers, and clinic staff
- Training materials and curriculum
- **Partners:**
  - Family and Community Health Bureau
  - HALI Project
  - Families with CYSHCN
  - PP Program Director and State Coordinator
  - Advocacy Groups
  - Caregiver Support Groups
  - Community Resources

Context: Fifty-two of 56 counties are designated healthcare professional shortage areas in the state of Montana. Many counties are rural and sparsely populated. Political will exists to improve care and outcomes of CYSHCN, of whom over half of households had incomes below 200% of the federal poverty level in 2006. PP Program clinics participate on a voluntary basis.

Activities

- Recruit Primary Care Practices that may serve as PPP Program sites
- Identify and train PPs & PP Liaisons
- Providers refer families to PP & Liaison
- PP Liaison activities
  - Liaise among PP-families-providers
  - Assess family needs
  - Communicate family referrals to PP
  - IT or EHR support for PP
  - Document actions
  - Promote PP within clinic and community
  - Assume duties of PP as appropriate and as needed
- PP activities
  - Liaise between families and providers
  - Proactive outreach to families in clinic
  - Assess family needs
  - Routine & consistent follow-up with families
  - Provide emotional support to families (listen, encourage)
  - Provide resources to families
  - Guide caregivers and families through processes (e.g. Transition Care, School IEPs, etc.)
  - Update community resource guide
  - Relate family experience to healthcare providers
  - Document actions
  - Promote PP within clinic and community
- Program Director and State Coordinator provide ongoing support to PPP staff

Outputs

- Trained, capable, supported PPP staff situated in clinics
- Families referred to PPP
- Resource guides are present and regularly updated
- Relationships developed among healthcare providers, PPP, and families
- Interactions between families and PPP and actions by PP are documented
- Monthly PPP group and individual calls, & biannual trainings
- Team-based approach to family-centered care
- Compassionate case management

S/T Outcomes

- Relationship/rapport established among caregivers, families, and healthcare providers
- Ease burden on family and healthcare provider practice
- Family satisfaction (Caregivers receive resources, feel supported)
- Families' adhere to care plan
- Provider satisfaction (patient load lessened)
- Visibility of PPP established (in practices and community)

M/T Outcomes

- Decreased caregiver stress: Decreased isolation, decreased anxiety, increased confidence, improved day-to-day "survival", & increased ability to make future goals
- Increased health literacy among families
- Reduction in unmet family needs (e.g. transition)
- Increased utilization of community resources
- Decreased provider stress through improved clinic efficiency
- Increased provider support for PPP
- Caregivers and providers proactively initiate contact with PP
- Improved communication and interdisciplinary collaboration between institutions (e.g. schools and healthcare providers)
- Better served patients in healthcare practice

Culmination of mid-term outcomes

L/T Outcomes

- Family self-sufficiency & empowerment to seek out resources and engage with the healthcare system
- Healthy advocacy (Caregivers are healthy advocates for CYSHCN) and shared decision-making
- Holistic healthcare
- Cost-savings in healthcare (Reduction in provider burnout; funds invested vs future healthcare savings)

ULTIMATE GOALS

- Improved outcomes for CYSHNC
- Improved Quality of Life for CYSHCN and families
- Improved Quality of System of Care/Medical Home for CYSHCN and families

Hope for Future & Joy for Life

Trust between PP and Family, and PP and Provider, as foundation

Assumptions: PP staff and healthcare providers turnover is low. Healthy boundaries are established between PP and families. Community resources exist. State funding will continue or grow to sustain the PP Program.

APPENDIX E

CDC/HARVARD EVALUATION RECOMMENDATIONS

Table 1. Evaluation Questions, Indicators, and Data Sources

Priority questions in are bolded; indicators are bulleted; potential sources of data are italicized.

Structure Evaluation	Process Evaluation	Outcome evaluation
What is the healthcare context in Montana for CYSHCN? ○ # of CYSHCN in MT ○ # of clinics serving CYSHCN in MT *National Survey of Children with Special Health Care Needs (NSCSHCN)*	What is the reach of PPP? ○ % of eligible practices with PPs ○ % of at-risk children who are referred to PPs (in total) *National Survey of Children with Special Health Care Needs (NSCSHCN)* What is the scope of PPP? ○ % of at-risk children who are referred to PPs at the practice level ○ % of at-risk children who are referred by each provider to the PPs ○ % of providers in the practice who referred at-risk children (corrected for # of at-risk children served) *Implementation of Standardized Screening Tool in Office Setting* *http://www.cahmi.org/projects/children-with-special-health-care-needs-screener/* How responsive are PPs when establishing contact?	**Family Satisfaction** ○ Level of satisfaction with the service provided by PP and medical team ○ Number of unmet needs ○ Level of perceived family support ○ % family initiated contact *Implementation of pre- and post-implementation surveys*, CHRIS **Provider Satisfaction/Stress** ○ Mean number of minutes spent discussing non-medical needs with ○ Level of satisfaction with the service provided (and potential outcomes observed) *Implementation of pre- and post-surveys* (and potentially CHRIS) **Caregiver Stress** ○ Changes in Impact on Family Scale

	○ Mean time taken for PPs to respond to referrals to PPP ○ Presence or absence of waiting list *CHRIS (and other form of documentations used by PP, e.g., excel, EHR)* Who are the recipients of PPP services? ○ % of families served who are from vulnerable groups (e.g., tribal pop, low SES groups, incarcerated parents, children in foster care, etc.) ○ % of families served by primary referral reason--i.e., what risk factors or medical conditions make families more likely to be referred to PPs? *CHRIS (and other form of documentations used by PP, e.g., excel, EHR) and Medicaid data* How consistent are the PPs in delivering their services? ○ Duration and frequency of contact with PPs (corrected for the total duration of relationship) ○ Mean delay from time of contact to documentation entry	○ Changes in Parent Experience of Child Illness ○ # of work days missed *Pre- and post-implementation: Family Impact Measure, Parent Experience of Child Illness (PECI)* **Cost Saving** ○ Total number of ED visits, inpatient and outpatient encounters ○ Total healthcare costs per child *Medicaid, CHRIS data* ***Other potential accountable outcomes should resources and time permit:*** Adherence ○ No show rates ○ % of referrals followed through in a timely manner ○ % of caregivers who drop out of the program or who refuse services *CHRIS & EHR* Health Literacy

	CHRIS (and other form of documentations used by PP, e.g., excel, EHR) Are PPs well supported in their roles? ○ Attendance rate of liaison and PPs in the mandatory monthly calls ○ Training evaluations: level of content quality and ability to meet PPs need *Roll calling, survey and/or interviews with PPs and liaisons*	○ Changes in health literacy score ○ Perception in ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions for their children *Pre- and post-implementation: Short Test of Functional Health Literacy in Adults (S-TOFHLA) and/or Rapid Estimate of Adult Literacy in Medicine (REALM)* Achievement of Medical Home ○ Changes in the score of medical home index. *Pre- and post-implementation: Medical Home Index (Pediatrics) and Medical Home Family Index*

Table 2. Proposed tools for evaluating key indicators

Key Measures	Indicators	Tools
Family Satisfaction	○ Level of satisfaction with the service provided by PP and medical team ○ Number of unmet needs ○ Level of perceived family support	**NS-CHSCN** https://www.cdc.gov/nchs/data/slaits/NS_CSHCN_Questionnaire_09_10.pdf Guide: http://childhealthdata.org/docs/cshcn/guide_to_topic_quests_asked_09_10_nscshcn_apr_2011-pdf.pdf?sfvrsn=5
	○ % family initiated contact	**(strengthening documentation practices in CHRIS?)**
Provider Stress/ Satisfaction	○ Mean number of minutes spent discussing non-medical needs with	**(strengthening documentation practices in CHRIS/EHR OR potentially self-report)**

	○ Level of satisfaction with the service provided -- level of providers' stress	**Physician Work-Life Study** http://www.d.umn.edu/~shel0210/Data%20Analysis%20Project/measuring%20physician%20satisfaction%20in%20a%20changing%20and%20challenging%20workplace.pdf **Pane, Davis & Ottolini, 2012 Hospitalists Survey (adaptation of Physician Work-life Study)** http://hosppeds.aappublications.org/content/hosppeds/2/3/141.full.pdf **Okunogbe et al., 2017 Tool** See Appendix E, Figure 1
Family Stress	○ Changes in Impact on Family Scale	**Impact on Family Scale** Tools are requested from Dr. Ruth Stein 1/10 Factors Measured: https://academic.oup.com/jpepsy/article/25/5/323/1014483
	○ Changes in Parent Experience of Child Illness	Parent Experience of Child Illness (See Appendix E, Figure 2)

	○ # of work days missed	**Self-report on # of work days missed**
Cost Saving	○ Total number of ED visits, inpatient and outpatient encounters	**CHRIS & Medicaid linkage** e.g., http://rimed.org/medhealthri/2009
	○ Total healthcare costs per child	

Table 3. Indicators and Success

Evaluation Question	Criteria or Indicator	Standards (What Constitutes "Success"?)
1.Family Satisfaction	Level of satisfaction with the service provided by PP and medical team	Improved
	Number of unmet needs	Reduced
	Level of perceived family support	Improved
	% family initiated contact	Improved
2.Providers Satisfaction/Stress	Mean number of minutes spent discussing non-medical needs with	Reduced
	Level of satisfaction with the service provided (and potential outcomes observed)	Satisfaction improved; with outcomes observed

3. Caregiver Stress	Changes in Impact on Family Scale	Improvements on subscales
	Changes in Parent Experience of Child Illness	Improvement on subscales
	# of work days missed	Reduced
4. Cost Saving	Total number of ED visits, inpatient and outpatient encounters	na
	Total healthcare costs per child	Reduced

Table 4. Proposed data collection methods

Method	Strengths	Limitations
Survey link emailed to parents at predefined time	• Responses could be received at approximately predefined time • Easier data management, as compared to call surveys	• Parents need to have access to the internet--might not be an issue as >88% of families in MT have access to the internet (File & Ryan, 2013) • Potentially low response rate (e.g., previous pre- & post-implementation surveys)
Survey administered through calls at predefined time	• Responses could be received at approximately predefined time	• Parents need to provide their phone number • Taxing for the surveyors • To be successful, calls need to be made at parents' convenient time • Potentially low response rate

Survey administered in paper/online format while waiting for appointment	● There is practically no opportunity costs for completing the survey ● Online: data could be managed more easily, and have potential for linkage to CHRIS and EHR; ● Online: potentially more responsive usage for the responses (e.g., evidence on electronic patients-reported outcomes, i.e., ePROs, in Boston) ● In paper: Does not depend on the availability of electronic device at the clinic ● High response rate e.g., evidence on electronic patients-reported outcomes, i.e., ePROs, in Boston (Rotenstein, Huckman, & Wagle, 2017 ● Has been found to be successful in gathering **routine** data on primary care needs (e.g., PHQ-9 depression, Edinburgh Postpartum Screen, Intimate Partner Violence), Behavioral health (AUDIT-C Alcohol Screen, Schwartz Outcomes Scale, GAD-7 Anxiety Screen), and Registration data (e.g., Preventative care vs. diagnostic care form, waiver and unpaid charges agreement form) (The Fenway Institute, 2017)	● Families have to show up to the appointments to complete the survey ● Surveys might be taxing if done after the appointment--timing of the survey administration needs to be **before** the appointment ● Online: limited to cellular internet connections of the parents while in the clinic (or program needing to lend an electronic device to the parent to complete the survey) ● In paper: data needs to be uploaded back to the internet for safekeeping

APPENDIX F

PARENT PARTNER CONSENT FORMS

Patient Name: _____ Birthdate: _____

AUTHORIZATION FOR RELEASE OF PROTECTED HEALTHCARE INFORMATION

Please check all applicable boxes

☐ I give my permission to **** Hospital to request information listed below from the Hali Project Program.

☐ I give my permission to **** Hospital to disclose information listed below to the Hali Project Program.

PURPOSE OF DISCLOSURE: To facilitate evaluation, treatment and aftercare services for the patient.

INFORMATION TO BE REQUESTED/DISCLOSED: Clinical Genetics Notes Office Notes Genetics Lab Results

Program Name:

The Hali Project Montana Parent Partner Program (MPPP)
Children's Special Health Services/Montana Department of Public Health & Human Services
P.O. Box 202951
Helena, MT 59620
Phone: 406-697-4631

This authorization will remain valid for a period of 12 (twelve) months from date of signature unless revoked before that time as described below. I understand that this authorization for release of information may be revoked at any time by sending such revocation in writing to the HIM Director at 2755 Colonial Drive, Helena, MT 59601. Shodair will comply with the revocation unless disclosure is required to effectuate payments for health care that has been provided or other substantial action has been taken in reliance on the authorization. Leaving treatment at Shodair against medical advice does not, in and of itself, constitute a revocation of this authorization for release of information. Shodair Hospital may not condition treatment or payment on whether an individual signs this authorization. The potential exists for information disclosed pursuant to this authorization to be re-disclosed by the recipient and no longer be protected by federal law. The undersigned person(s) agree to indemnify and hold harmless Shodair Hospital and its employees from all claims or liability that may arise as a result of Shodair's compliance with this authorization.

_____ _____
Date Signature of Parent/Legal Guardian (Circle Applicable Status)

_____ _____
Witness Signature of Patient

PROHIBITION ON REDISCLOSURE: This information has been disclosed to you from records whose confidentiality is protected by Federal Law. Federal Regulations (42 C.F.R.) Part 2 prohibit you from making any further disclosure of this information except with the specific written consent of the person to whom it pertains. A general authorization for the release of medical or other information if held by another party is not sufficient for this purpose. Federal Regulations state that any person who violates any provision of this law shall be fined not more than $500 in the case of the first offense and not more than $5,000 in the case of each subsequent offense.

PublicHealth IN THE 406 MONTANA CHILDREN'S SPECIAL HEALTH SERVICES

Release of Information (ROI) and Consent to Participate
Please complete the form and provide us with the most current information.

If appropriate and with your consent, Shodair Medical Genetics may refer your family to the Montana Parent Partner Program. A Parent Partner is a parent of a child with special healthcare needs who is personally experienced and professionally trained to help you navigate your child's care. Parent Partners share their knowledge with you, and your child's healthcare providers, so you can better support the dreams and progress of your family.

Parent Partners will help your family break through the isolation and uncertainty you may experience. They will help you connect to resources so your child and family can be more fully supported in your community. Parent Partner family support allows clinic workers and healthcare providers more time to focus on your child's health and wellness.

Parent Partner services are always provided at no cost to you and your family.

A Parent Partner can:

- Assist your family in finding community resources, such as transportation, therapies, food and housing.
- Help you navigate your child's special healthcare needs.
- Help you communicate more effectively with your child's healthcare providers.
- Connect you with people and programs to help you better understand your child's rights in the school system and in special education.
- Support you in becoming an advocate for your child.
- Help you plan your child's transition from pediatric to adult healthcare.

For more information, please visit **thehaliproject.org** or **montanaparentpartners.org**

Release of Information and Consent to Participate:

I parent/legal guardian give consent for the above named individual to participate in The HALI Project Montana Parent Partner Program (Montana Parent Partner Program – MPPP). I give the above named providers permission to release medical records to the MPPP. I give the MPPP permission to share health information generated through participation in the program with our child's care providers for the purpose of providing our child with continuing care. I understand that the MPPP is sponsored in conjunction with CSHS of the MDPHHS. Permission is further granted to enter information gathered from interactions with MPPP into a statewide data system for children with special health care needs for program analysis, data reporting and research done in aggregate. No information that contains identifiers may nor will be disclosed from this database for any purposes other than for the provision of health care and the evaluation of the MPPP. This authorization is effective until it is revoked in writing.

Patient Name: _____ **Date of Birth:**_____

Signature: _____ **Date:** _____

Print name:_____ **Relationship to Patient:** _____

Best Day of Week and Time for Parent Partner to Call:_____

Right to Revoke:

You have the right to revoke this Release of Information and Consent at any time by submitting your written revocation to the clinic. Please understand Revocation of this Release of Information and Consent will not affect any prior action taken by CSHS or the clinic permitted by the Release of Information and Consent before receiving your revocation or disclosures required by law. MPPP program may discontinue service if consent is revoked.

Shodair Genetics Office Use Only

Received By:	Date:	

"This project is 100% supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under CFDA #93.994 for Maternal and Child Health Services, the total HALI Project Parent Partner Program award amount 10-1-2018 to 9-30-2020 is $659,563. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government."

APPENDIX G

MTPPP REFERRAL IMPROVEMENT PLAN

MTPPP Referral Improvement Plan

COMPONENTS OF THE MODEL

Pre-Implementation (4 months) August 2021-December 2021

Identify Stakeholders and develop Core QI Team
Identify broad group of stakeholders. Organize QI Core Team including provider champion, clinic leadership, Parent Partner, genetic counselors, EHR informatics, and Title V representative.

Educate Team & Practice Location
Host in-person training for Core QI Team.

Data Collection
Clinic location, MTPPP and CSHS partner to provide baseline data. Results help guide areas for improvement and development of implementation plan.

Technical Assistance
Connect with Peers for Progress researcher, Montana Parent Partner Program and Children's Special Health Services.

Implementation (2 months) January 2022-February 2022

Implement New Process Flow
Pilot new workflow and referral process during three genetics clinics.

Analyze
Gather information and feedback on process after each clinic. Continuously assess functionality of process and adapt appropriately.

Pilot Got Transition Tools
Utilizing PDSA cycles, continuously assess functionality of tools and adapt appropriately.

Wrap-Up (2 Months) March 2022-April 2022

Data Collection
Analyze data collected on Excel spreadsheet. Metrics include: Patients between the ages of 0-21 years evaluated in the clinical setting; Number of providers who requested consent forms be sent to caregivers; Number of caregivers sent consent form; Number of caregivers who returned consent form; Number of referrals sent to the MTPPP. Number of caregivers the PP contacted.

Present Results
Present results to Core QI team and stakeholders.

Expansion
Discuss expansion to other MTPPP host clinics.

APPENDIX H

DETAILED TIMELINE

Start Time	Project Goal	Activity	Expected Completion	Person Responsible
08/25/2021	Coordinate quality improvement process and understand problem	Meet with practice site location: Discuss problem and the specific site.	09/30/2021	Project leader
		Meet with CSHS. Discuss problem at the state level.		
		Meet with Peers for Progress. Discuss problem at the national level.		
09/15/2021	Gain EHR Access	Meet with practice location EHR team and set goals.	10/01/2021	Project leader, Parent Partner, EHR team.
		Meet with practice location EHR team and Parent Partner to define success and brainstorm workflow.		
10/15/2021	Educate Champion QI Team	Educate Champion QI team on background and problem.	10/15/2021	ALL champion QI Members.
10/20/2021	Brainstorm	Project leader to work with practice location staff to brainstorms ways to improve workflow and referral process.	10/20/2021	Project leader and practice location staff.

10/20/2021	Develop improvement tools, find screening tool, and draft workflow process	Project leader to draft data collection excel spreadsheet, find valid and reliable screening tool, and draft new workflow process.	11/15/2021	Project leader.
11/15/2021	Solidify workflow and referral process	Project leader to propose workflow and referral process changes to practice location.	12/01/2021	Project leader and practice location staff.
		Project leader to receive feedback on workflow and referral process changes.		
		Project leader to integrate feedback on workflow and referral process changes.		
01/03/2021	New Workflow Process Initiated	Begin using excel data collection spreadsheet, PIP screening tool, and new workflow and referral process.	Ongoing	Project leader and practice location staff.
01/17/2021	Check-in	Assess the progress, analyze data, and meet as a team to discuss any needed improvements.	01/17/2021	Project leader and practice location staff.
01/31/2021	Check-in	Assess the progress, analyze data, and meet as a team to discuss any needed improvements.	01/31/2021	Project leader and practice location staff.
02/14/2021	Check-in	Assess the progress, analyze data, and meet as a team to discuss any needed improvements.	02/14/2021	Project leader and practice location staff.
02/28/2021	Check-in	Final: Assess the progress, analyze data, and meet as a team to discuss any needed improvements.	02/28/2021	Project leader and practice location staff.

03/01/2021	Analyze data	Project leader to analyze final data and prepare presentation.	04/15/2021	Project leader.
04/16/2021	Present Findings to Champion Team	Project leader to present findings to Champion team.	04/16/2021	Project leader and Champion team.