

PROGRAM REPORT

THE MILWAUKEE PROGRAM:

The Pediatric Complex Care Program (CCP) at the Children's Hospital of Wisconsin (CHW) / Medical College of Wisconsin (MCW)

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ABSTRACT

Objective: Describe the complex care program at the Children's Hospital of Wisconsin, Medical College of Wisconsin – history, current structure, outcomes, research / quality improvement projects, and finances.

History: Program started by Dr. John Gordon and Holly Colby, RN Program Manager in 2002.

Current Structure: Program serves ~650 CMC and their families through care coordination and medical co-management in both the ambulatory and inpatient environments. Team is composed of Care Coordination Assistant-RN dyad with the RN as the families' main point of contact. Each patient also has a faculty physician or APNP serving in conjunction with the patient's assigned dyad. Clinical Research Coordinator, Social Workers, and administrative staff support the program.

Outcomes: Favorable satisfaction ratings from families, primary care providers, subspecialty colleagues; cost savings identified by pre-post analysis.

Research: Primarily focused on program function, financial outcome, and clinical and family impact.

Finances: Hybrid value-volume based reimbursement structure.

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INTRODUCTION

The intent of this article is to provide a brief synopsis of the pediatric complex care program (CCP) at the Children's Hospital of Wisconsin (CHW) / Medical College of Wisconsin (MCW), "The Milwaukee Program." We describe the program's history, expansion and current structure after a Health Care Innovation Award (HCIA), recent outcomes, ongoing and future areas of research / quality improvement, and our thoughts on how the care of children with medical complexity can serve as a model for the enhancement of care delivered to all children. We strive to define "value" as the improvement of health for a population, one child and family at a time.^{1,2}

HISTORY

The Milwaukee Program was co-developed in 2002 by Medical Director Dr. John Gordon, a pediatric critical care physician from MCW, and Holly Colby, RN MS CNS, Program Manager from CHW. As an intensivist, it was not difficult for Dr. Gordon to appreciate the growing population of children with medical complexity (CMC), often tied to technology and with frequent admissions to the pediatric critical care unit (PICU).³ The hospital was very good at doing what it was designed for, treatment

and discharge; but not well-equipped to optimize the ongoing health of CMC and the function of their primary caregivers, their families. The Special Needs Program (SNP), as it was originally titled, was designed to be a tertiary care – primary care partnership, assuring that each child would have comprehensive care. SNP provided care coordination services, helped families negotiate the maze of medical and community services, facilitated communication, provided medical co-management with pediatric subspecialists, and provided a single point of contact 24 hours a day for the child's health needs. The program brought services to children in their home, ambulatory, and inpatient environments.³

The Milwaukee Program, along with other early complex care programs began to publish reports illustrating the cost savings associated with CMC enrollment.⁴ With CMC being pediatrics' "super-utilizer" high cost population, Wisconsin Medicaid came to appreciate the effective management and associated cost savings for children in the Milwaukee Program.³ In 2006, Wisconsin Medicaid began paying a small monthly care coordination fee to program nurse coordinators and physicians in an effort to encourage growth of the program in support of CMC in Wisconsin. Leadership at CHW

and MCW were also early and strong supporters of the SNP, advocating for and providing “gap funding” that sustained the program when the program’s revenue did not cover expenses, funding that they continue to provide as needed today.

HCIA EXPANSION AND CURRENT PROGRAM STRUCTURE

In a further effort to build upon the demonstrated favorable clinical and financial outcomes produced by the Milwaukee Program, Wisconsin Medicaid was awarded a Health Care Innovation Award (HCIA) in 2014 entitled, “The Special Needs Program for Children with Medical Complexity.”⁴ The award brought together the Milwaukee Program, Wisconsin Medicaid and American Family Children’s Hospital (AFCH) in Madison. HCIA awards grew out of the Affordable Care Act with an intention of exploring new service delivery and payment models leading to “better health, better health care, and lower costs” with a focus on unique populations with historically poor outcomes.⁵ The grant objectives were to (1) extend the Milwaukee Program’s model to a larger number of Wisconsin CMC by expanding capacity in the Milwaukee Program and starting a similar program at AFCH and (2) use the expanded service population data to

support the development of an innovative payment model for the population going forward. The population served prior to the HCIA award was approximately 200 CMC and their families; the Milwaukee Program is now serving over 650 CMC and their families. During the HCIA period Dr Gordon retired, and leadership transitioned to Dr. Timothy Corden, also a critical care physician.

PROGRAM ENTRY (Enrollment Criteria)

Children may be referred to the Milwaukee Program by anyone identifying the need for services, such as a PCP, subspecialists, bedside nurse, school nurse, or the family themselves. To enter the Milwaukee Program a child must meet both complexity and fragility criteria. *Complexity*: chronic conditions involving three or more organ systems and at least three subspecialists attending to the child’s care. *Fragility*: one or more inpatient admissions totaling at least five days or 10 subspecialty clinic appointments within the year prior to enrollment. For children entering the program out of the neonatal unit, clinical judgement is used to project anticipated fragility. Although not a formal component, social complexity (e.g. parent / guardian support at home, medical literacy, food and housing security, child protective services) is also taken into consideration when

considering program entry. Enrollment is voluntary for families, and children are rarely enrolled if their care coordination needs are met by another program within the CHW/MCW system.

ENROLLMENT VISIT and establishment of the primary complex care team

Each child and family meet with their primary complex care team face-to-face for an initial 90-minute enrollment visit. The team consists of a CCP medical provider, who is a faculty physician or advanced practice nurse practitioner (APNP), an RN care coordinator and a care coordination assistant (CCA). Care coordination assistants are not required to have a degree, many are Certified Nurse Assistants and most come to the complex care program from administrative supportive roles within CHW and therefore know the CHW system well.

The RN and CCA function as a standing dyad for all the children they care for. Typically, prior to the enrollment visit the CCP physician or APNP prepares by reviewing the child's medical record including outside records when available, a potentially lengthy process. At the visit, a medical history and exam is documented by the physician or APNP; the RN and CCA explore resources, social impacts, catalog

medications and technologies, review community interactions, and insurance needs and create an RN/CCA care plan that is included in the initial documentation. The primary products of the enrollment visit are a detailed medical assessment and plan by systems including documentation of family goals, and a to-do list table. These items, along with the social and resource notation from the RN and CCA, make up the child's Plan of Care. The provider also reviews and edit the child's problem list in the EHR and creates a brief summary of the child's medical state referred to as the Care Coordination note (see inpatient section for details of Care Coordination note). The team spends an average of 13.5 hours total time in the first month on the review, enrollment visit, and developing the Plan of Care.

ONGOING CARE

After the enrollment visit, the complex care team sets about helping the family put their Plan of Care into action. The "go to" contact for families is the RN-CCA dyad, with frequent contact by phone, through EHR messaging, or in person. The RN triages family questions, brings in the complex care physician or APNP as needed to assist with medical concerns, attends key subspecialty appointments and care conferences with families, and works with the CCAs to

arrange clinical appointments, work through community resource needs including insurance, school, home health and respite accommodations. The addition of the CCA was a key component of the grant expansion. Prior to the CCAs being added to the team, RN caseloads were capped at 35-40 families; with the addition of the CCA the RN/CCA dyads now care for up to 90 families. The Milwaukee Program currently has nine CCA-RN dyads. For complex social issues the program also has 1 FTE dedicated social work professional for the team and family to utilize. Families are contacted by their CCP team's CCA at least once per month to check in on the child's health and ongoing needs, and the RN calls shortly after each inpatient admission. After enrollment, children are seen in the CCP clinic at a minimum of every six months to update their Plan of Care.

Program physicians and APNPs are actively involved with medical co-management once a child is enrolled. The CCP physicians and APNPs work closely with the child's primary care physician and subspecialists, offering a holistic perspective for the child's care, helping to optimize the interaction of all the different types of care being delivered. Over time, the primary CCP physician or APNP often becomes the person who knows the child's tertiary medical perspective the best.

Families come to value the CCP provider as a trusted advocate for medical decisions. The trusting relationship developed between families and their CCP team is felt to be the foundation for the program's effectiveness. The Milwaukee Program also continues to offer a 24-hour phone access for families to reach a CCP provider at any time to discuss urgent health care concerns.

Patient panel sizes per FTE are ~80 for APNPs and ~65 for faculty physicians; faculty ratios are lower due to their responsibilities beyond clinical work and also to accommodate the time needed to serve as collaborating providers for the APNPs. Currently the Milwaukee Program has nine APNPs representing 8.5 FTEs and three physician faculty representing 2.75 FTEs with two open fulltime faculty positions.

Patient graduation from the program is discussed if a child no longer meets criteria, or if the CCP team and family feels they no longer need programs services. Transitioning children to adult care as they age beyond the traditional pediatric time range remains a challenge.

INPATIENT SERVICE

The Milwaukee Program's inpatient service consults on all program enrolled-children

admitted to CHW, participating during bedside rounds and documenting daily progress notes.

The team also is available to consult on children being seen in the emergency department. Daily CCP inpatient census prior to the HCIA award averaged ~8 patients; the current average is over 20 patients with spikes to over 40 children during respiratory season. The CCP providers rotate through inpatient service, with one CCP faculty physician and two APNPs on service at any time. The faculty physicians are on service for a week at a time and are the identified collaborating physician for the APNPs for that week. For inpatient continuity, APNPs also try to schedule their inpatient time in week blocks. The inpatient team brings historical knowledge of the child's medical and social situation to the inpatient environment, emphasizing what has worked or not worked in the past, awareness of medications and baseline technical equipment needs and settings, and knowledge of what the child is like when well and when ill. The team can aid the primary admitting service with management decisions, smooth out environment of care transitions, and are strong advocates for a family's knowledge and wishes for their child. Because a child's primary complex

care physician or APNP may not be on inpatient service when a child is hospitalized, the inpatient staff remains in contact with the primary complex care team when needed. The child's primary CCP team – physician or APNP, RN, and CCA communicate regularly with the inpatient team to discuss care and visit the child and family in the hospital when the team member's time allows.

The CCP inpatient team and our other hospital colleagues are reliant on the documentation and input from the child's primary CCP team. The Milwaukee Program is continuously trying to optimize our various note templates to provide useful and easily-accessible information to aid each child's care; documentation impact is also an active area of research (see next section). All of The Milwaukee Program's note templates are available on request, including: *inpatient consult*, *daily rounding*, *hospitalization summary*, and *care coordination* notes. The *hospitalization summary* lives as a shared document during the hospital stay and is updated daily by the physician or APNP seeing the child; at discharge, the document is edited for clarity, signed, and routed to the child's primary complex care team. The *care coordination* note (figure 1) is a brief summary that highlights who the child is and what a

Care Coordination Note Template
Enrolled in Complex Care Program
Who am I? (Why am I complex)
Functional status when well
Baseline abnormal physical findings, vital signs, lab values
Well plan and Sick plan for home management
ED / hospital recommendations including rescue plans and preferred admitting service/unit
Peri-Operative Recommendations

Figure 1. Care Coordination Note template

caregiver needs to know to directly render care; the note is also strategically placed within the EHR to make it hard to overlook. The “who am I and why am I complex” initial portion of the *care coordination* note is intended to influence hospital culture to view children with medical complexity as individuals with distinct stories and not simply as a group of chronic conditions. Creating the *care coordination* note also allows us to reach out to our subspecialty colleagues to help formulate and update action or sick plans; a process that not only improves care but also fosters a team approach across subspecialties.

PAYMENT MODEL

Through the HCIA grant process our program along with our CMC partners at AFCH developed a strong relationship with our assigned WI Medicaid team. Payer and clinician partners developed trust in each other, an understanding of the clinical goals and the process needed to serve CMC and their families, and an appreciation of each

other’s position on what was and what was not possible regarding a payment model.

This relationship was the main reason behind the successful negotiation of a sustainable payment model, achieving one of the HCIA goals. Details of the plan can be found at

<https://www.forwardhealth.wi.gov/kw/pdf/2018-13.pdf>. Of note, it became apparent to

Wisconsin Medicaid and the other HCIA partners that the actuarial risk presented by the small and highly volatile CMC population was too great for a health care system to enter into risk-based contracting. Instead, the model continues to allow the complex care programs to bill fee for service for face-to-face encounters, but now also pays a team-based sum for previously non-reimbursable care coordination time and effort. Support for the payment structure was heavily reliant on time-based studies, which documented the amount of time each CCP team member spent on each individual patient as well as other CCP general patient-related activities on a daily basis. With this data, a relatively simple model was developed based on the costs of the program (i.e. time and personnel required to deliver the CCP services) and the impact of the CCP services on health care costs. Two team-based payments were established: an *enrollment fee* for effort surrounding the enrollment visit and

development of the initial Plan of Care; and an *ongoing fee*, a monthly payment for all enrolled children with a meaningful interaction with the program. The payment model outcome reflects Dr. Gordon's initial simple yet elegant concept, "the program saves money, the program costs money, make the program sustainable and it will continue to save health care dollars beyond its costs."

Although the current model is not considered innovative to some audiences, we feel this team-based payment structure offers novel and unique advantages by ensuring payment for all essential personnel involved in the care of CMC (research coordinator, administrative assistants, CCAs, RNs, physicians and APNPs). The payment model aligns incentives for the team approach - all members are needed for a positive clinical outcome and are valued. Both of our oversight clinical/financial centers, CHW (RNs, CCAs, Social Workers) and MCW (physicians, APNPs, administrative assistants, research analyst) also had to work collegially on apportioning the new fees relative to the effort of the employees of each parent institution - useful institutional learning that can be applied to future value-based contracting.

OUTCOMES

We regularly report outcomes that reflect our stakeholders' desires and goals: primary care physicians, subspecialty colleagues, affiliated institutions (CHW, MCW), primary payer (WI MA), and most importantly the children and families we serve. The program sends out annual satisfaction surveys to partnering primary care physicians and enrolled families; we also receive similar information from the CHW/MCW annual survey reflecting all subspecialty areas. We engage in financial analysis with information provided by our institutions (resource use, costs, payment and billing data), along with claims information provided by our primary payer, Wisconsin Medicaid, through an ongoing data sharing agreement. The institutional and Medicaid data have allowed us to do pre-post enrollment evaluations of total cost of care and the contributing components. Although pre-post methodology has flaws including regression to the mean and not being able to attribute changes solely to CCP enrollment we are buoyed by how closely our financial outcomes match controlled studies.^{4,6} We continue to search for a valid control group to demonstrate greater rigor for an analysis. Fortunately, the pre-post approach has offered enough credibility in the eyes of our primary payer to

not wait for the perfect to bring sustainable financing to the care of Wisconsin's CMC population.

Summary of most recent outcome data:

Primary Care partner survey, 2018:

- 140 responses, 40% response rate.
- 93% of respondents very satisfied or satisfied with program service.

Family survey, 2018:

- 159 responses, 25% response rate.
- 97% of respondents very satisfied or satisfied with program service.

Financial impact to WI MA:

- *n* of 352 children, pre-post analysis, 9/1/14-8/31/17.⁷
- Savings of over 25 million dollars per year.
- Reduction in inpatient utilization accounts for over 90% of the savings.

RESEARCH / QUALITY IMPROVEMENT

The Milwaukee Program has a strong history of contributing to the still relatively young complex care subspecialty. Our goal is to remain good stewards and continue to make contributions where our strengths allow. We primarily focus our research and QI projects on how we bring value to the local population and stakeholders we serve.

The program benefits from our active family advisory council in planning our research and QI agendas. Below is a list of active projects with brief descriptions. We encourage anyone interested in collaborating on these ventures or learning more about them to contact us.

Inpatient

- Explore the value the complex care program brings to different inpatient environments of care, starting with the hospitalist service, and to families while in the hospital. Goal is to optimize CCP efficiency as the program grows and to ensure that growth is not adversely affecting the quality of care.
- Comparative study of CCP impact on the pediatric critical care unit (PICU) environment of care; patient safety, utilization, and family satisfaction in tertiary care centers with and without active CCP programs.
- Impact of pharmacy personnel involvement on CMC compliance and safety of medication use.

Documentation

- Internally, along with hospital EHR staff we are formulating a living note that represents CMC by systems.

The goal is to make documentation more efficient and to better represent the complexities of the patients to all involved in their care. We still struggle with the use of a systems approach vs problem list approach in the EHR.

- Development of a longitudinal inpatient care plan generated with families, allowing them to indicate what does or does not work for their child's care. The project is intended to capture the knowledge families have about how to best care for their children given their vast home care experience, e.g. schedule for cares and feedings, optimal communication approach, representation of child when well. The goal is to create a reference for inpatient caregivers, reduce the family burden of having to repeat information with each new encounter, and ultimately for families to easily update the document electronically.

Perioperative program

- The CCP provides perioperative consultation for enrolled and non-enrolled CMC, primarily for orthopedic and neurosurgical procedures. In conjunction with

surgical, anesthesia, critical care, and hospitalist teams, we are examining effects on utilization (LOS, readmission rate) and outcomes of care (post-operative complications, healing time).

Family Support and Wellness

- Impact of CCP on family-care team dynamics in the PICU environment, in collaboration with critical care, palliative care, and psychology colleagues from CHW, MCW and the University of Wisconsin-Milwaukee.
- Implementing a Trauma Informed Care approach using the Sanctuary Model in collaboration with the CHW social work and community services departments. Goals are to 1) promote CCP staff resilience as an aid for avoiding burnout by fostering a trauma-informed culture, and 2) encourage a trauma-informed approach to caring for families and CMC: identifying trauma histories, helping children and families to process traumatic events, and preventing re-traumatization in the health care setting.
- Understanding the value the CCP provides to families, what helps families the most, what would you

miss if the program was not here?
Project is being done in collaboration with psychology department at Marquette University. The goal is to improve CCP efficiency, directing activities to those most important to families while trying to support wellness and build resilience.

- Collaborative for Improvement and Innovation Network (CoIIN) to Advance Care for Children with Medical Complexity, a four-year HRSA learning cooperative with nine other states. The WI team consists of our partners at AFCH, Department of Family and Health Services, Family Voices of Wisconsin, Children and Youth with Special Health Care Needs Regional Centers, and parent representatives. The project goals are focused on reducing unmet needs by helping families connect with their local regional centers and enrolling in the Medicaid Children's Long Term Support waiver. The team is also working on developing an approach that helps families come to meaningful and attainable goals for CMC.
- Development and testing of a mobile app based on the Bridge to Independence family care

coordination curriculum

(<https://www.chw.org/medical-care/special-needs-services/bridge-to-independence>), in collaboration with colleagues from the University of Wisconsin-Milwaukee and Universidade Federal do Rio Grande do Sul in Brazil. This app is being produced and piloted in English, Spanish, and Portuguese.

CMC Finances

- Ongoing analysis of CCP-enrolled patients using institutional information and Wisconsin Medicaid claims data.
- Defining the financial revenue impact of CMC on the health care system and how changes in reimbursement for this high utilizer population can impact care for all children across a pediatric enterprise.

DEFINING HEALTH CARE VALUE

In a health care environment era where a positive financial margin is increasingly viewed as a growing portion of how success is defined, it is worth noting a company's positive financial return is associated with the company's purpose, and clarity of

purpose transmitted to their employees; inspiring the company's workforce to maintain strong beliefs in the meaning of their work.⁸ John Gordon and Holly Colby started the Milwaukee Program "because it is the right thing to do for these children and families" and with a strong belief that medical co-management and intensive care coordination will ultimately improve health, health care delivery, and the costs of care. The Milwaukee Program continues to strive to improve health outcomes for CMC and support the wellbeing for their families as our purpose. We are confident that the value elements needed for financial sustainability will continue to follow. CMC care crosses almost every aspect of a

pediatric tertiary care institution's work and is impacted by multiple community resources. Complex care programs are ideally positioned to serve as examples for how team-based care across medical environments and in the community can improve health and family function as a primary goal, favorably bend the cost curve and contribute to a positive financial margin for their respective institutions. Do the right thing and good things happen. We invite interested groups to visit us in Milwaukee so that we can continue to learn from each other, and together continue to do good things for children with medical complexity and their families.

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FIGURES

Figure 1.

Care Coordination Note Template

Enrolled in Complex Care Program

Who am I? (Why am I complex)

Functional status when well

Baseline abnormal physical findings, vital signs, lab values

Well plan and Sick plan for home management

ED / hospital recommendations including rescue plans and preferred admitting service/unit

Peri-Operative Recommendations

The goal of this brief note is to make information readily available to immediately care for a child with medical complexity. The note is intended to be short and to the point. The Care Coordination Note lives at the top of the problem list section within Children's Wisconsin's EHR; one or two "clicks" to access (this could be better). The note is routinely updated at the comprehensive Complex Care Program (CCP) outpatient visits every 6 months and at hospital discharge. The CCP encourages subspecialty colleagues to contribute to the note; they are cited as the source of recommendations. Day of the last update is also displayed.

Sections:

Who am I? – This is a brief, few sentence description of the child's medical conditions; e.g. toddler male, former 23 week premature neonate, IVH history with subsequent hydrocephalus, VP shunt, past multiple revisions, seizure disorder, chronic lung disease, tracheostomy device in place, on home mechanical ventilation support, G-tube dependent for nutrition, exhibits dysautonomia when ill.

Functional status when well – Describes family's and CCP staff's impression of the child when well; e.g. smiles with familiar voices, enjoys company of family pet, enjoys taking tastes of food, loves to hear books and music, laughs with siblings, understands

everything but cannot vocalize. The goal is to humanize the child to the care team, the things they may never see when the child is ill, what to look for as the child improves.

Baseline abnormal physical findings, vital signs, lab values – Describes baseline findings that in general may be seen as abnormal by caregivers that are not familiar with the child but are actually part of the child's conditional baseline e.g. rt pupil is always dilated, persistent nystagmus, left sided weakness, copious secretions common, heart murmur, body temperature 96 F, 35.5 C - "normal" temperature may indicate fever, typical pulse oximetry saturations, seizure frequency and duration, platelet count runs low 50-100K.

Well plan and Sick plan for home management – These are listed per organ system or condition most imperative to the child's well being e.g –

Respiratory -

Well plan: baseline pulmonary hygiene (aerosol type and frequency, CPT – vest, IPV, cough assist); home O2 use – delivery, FIO2; mechanical ventilation mode, settings, tracheostomy device specifics.

Sick plan: escalation of pulmonary hygiene frequency and additions to baseline care, degree of upper O2 titration, aerosol frequency, CPT mode escalation; upper limit of when to call medical support, or bring to medical care.

Neurology –

Well plan: seizure medications, ketogenic diet,

Sick plan: use of emergency benzodiazepines, escalate dose of Keppra at sign of illness or fever, when to seek medical attention.

Metabolic –

Well plan: special formula need, frequency of feedings, glucose checks; adrenal function.

Sick plan: When to seek medical attention to support metabolic needs, unable to tolerate nutrition, need for adrenal steroid support when ill.

ED / hospital recommendations including rescue plans and preferred admitting service/unit –

Similar to well and sick plans above, subcategorized by condition or organ system affected e.g.

Seizures – check glucose, often hypoglycemic with prolonged seizures, responds best to barbiturates instead of benzodiazepines, may need to support the airway when adding additional anticonvulsants; VP shunt in place, malfunction often presents with seizure activity.

Metabolic – if presenting with metabolic acidosis, must immediately establish IV access and start following IV fluid to maintain GIR of ...; Adrenal insufficient give the following steroid support when ill / stressed.

Cardiac – has a history of pulmonary hypertension, support saturations to at least 95%, call cardiology service for consultation. LVOT obstructive lesion, may not tolerate anemia or hypovolemia well.

Difficult IV access – move quickly to PIC line placement with IR or IO placement in emergency

Difficult Airway – small jaw, see anesthesia note dated ... for details; consider initiating difficult airway protocol if artificial airway is needed.

Hospital area – PICU placement due to mechanical ventilation needs, usual location in PICU ...

Peri-Operative Recommendations – Immediate considerations for a child needing to undergo a procedure, e.g.

Difficult Airway – small jaw, past experience required fiber optic assistance, see anesthesia note dated ...

Consider cardiac anesthesia consult due to underlying condition ...

Adrenal support, stress steroid use

Difficult IV access, required IR supported PIC line in the past



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