



Family-centered care for children with medical complexity: A goal-planning initiative

Abstract: NPs piloted a family-centered goal-planning tool with a medically complex pediatric population during outpatient clinic visits. The tool was an effective reminder to discuss goals after trust and rapport are established between provider and family.

By Kathy Lindstrom, DNP, APRN, FNP-BC; Rhonda Cady, PhD, RN; and Andrea Bushaw, PhD, RN, CPNP

An outpatient complex care clinic serves children and young adults with complex medical conditions and technology dependence. The primary objective of this clinic is maximizing health maintenance by helping families identify unmet needs and corresponding goals for their child's care. A gap analysis identified a lack of a standard method for identifying and documenting goal discussions with families. It also revealed the need to broaden the scope of these discussions to include family-centered goals. Although the project was conducted with a medically

complex pediatric population, the intervention and process tools are applicable to any population where goal setting, discussion, and documentation are priorities.

Children with medical complexity (CMC) have multiple chronic conditions and functional limitations, and require high healthcare and related service use.¹ Representing a small subset of children and youth with special healthcare needs, less than 1% of US children are considered CMC, but they account for as much as one-third of overall pediatric healthcare

Keywords: care coordination, care fragmentation, children with medical complexity (CMC), chronic conditions, goal planning, Iowa Model, Triple Aim

spending.^{2,3} CMC require integration of primary care, specialty care, and community resources to maintain health and optimize quality of life, but the array of providers and services frequently lead to care fragmentation.^{1,4,5}

The Triple Aim, developed by the Institute for Healthcare Improvement, is a framework used globally by healthcare organizations to simultaneously improve overall population health, reduce healthcare costs, and improve the patient-care experience.⁶⁻⁸ Care coordination is a recognized strategy to achieve the Triple Aim.⁹ It is evidence-based and incorporates assessment, goal setting, care planning, and continuous monitoring to reduce care fragmentation.¹⁰⁻¹²

For populations with chronic and/or unpredictable health conditions, goal identification, discussion, and planning help families and providers identify priorities and improve communication.¹³ These essential elements of care coordination assist in identifying patient strengths, care gaps, and activities that matter to CMC.¹⁴ Family functioning and family health are important health outcomes for CMC.¹⁵ Understanding family strengths and needs, and identifying obtainable goals that optimize family caregiving are identified research priorities.¹⁶

Clinicians need skills and tools to engage the family and encourage participation in care decisions, including goal planning.¹⁷ NPs are well positioned to deliver family-centered care coordination, including goal identification.¹⁸ NP scope of practice is grounded in critical thinking and problem solving, ideal for addressing the health and psychosocial needs of medically complex populations.¹⁹

This evidence-based, quality improvement (QI) project piloted a family-centered goal-planning tool in a complex care clinic. The Iowa Model, which is used to guide system changes, was the evidence-based practice model used to achieve this aim.²⁰ When a need has been identified, the Iowa Model supports gathering and synthesizing evidence to support a change, then piloting the proposed change, and finally assessing and evaluating the change. If the pilot is successful, results are disseminated and followed by widespread implementation. Additionally, a Plan-Do-Study-Act (PDSA) model was used to improve and accommodate operational aspects of the intervention.²¹ Following the principle of evidence-based practice, current evidence, patient preference, and clinician expertise were considered in the pilot evaluation.

■ Methods

Setting. The setting for this project is an outpatient complex care clinic that serves CMC up to age 26 years. The clinic is in a nonprofit, independent midwestern health system that provides specialty and subspecialty inpatient and outpatient services to children and adults with childhood-onset disabling conditions. Commonly treated conditions include cerebral palsy, epilepsy, muscular dystrophy, brain and spinal-cord injuries, spina bifida, and other genetic anomalies. A detailed description of the clinic and the role of the NP in the clinic was previously published in the June 2020 issue of *The Nurse Practitioner*.²²

All complex care clinic appointments are conducted by dedicated physicians and NPs. Due to patient complexity and comorbidities, the initial clinic appointment is 2 hours with a primary focus on developing a patient-centered care plan and roadmap that coordinates the various aspects of a child's care. The evaluation also addresses ongoing medical care needs, community resources, as well as communication and coordination with primary care and subspecialists. Subsequent clinic appointments occur every 6 to 12 months, are 1 hour in duration, and include a review of the child's condition and modification of the care plan and roadmap as needed. Primary care provider (PCP) partnership is promoted with a verbal handoff from the complex care provider to the PCP after every clinic visit and whenever the plan of care changes.

Stakeholders for this project included all complex care clinic staff (physician and NP providers, nurses, and the care manager and administrative assistant), the organization's nurse researcher, and the project leader. Secondary stakeholders included the families of patients seen in the clinic. Complex care clinic NPs and physicians are skilled at facilitating goal discussions focused on medical or clinical need. These discussions are documented in the electronic health record (EHR). Review of documented goals during a state-level medical home certification evaluation revealed the need for a consistent method of discussing and documenting goals during the initial clinic visit and a consistent approach for follow-up at future clinic visits.

Based on review and synthesis of the literature, the Post-Encounter Action Grid was chosen as a tool to address both concerns.²³ The tool was developed by Boston Children's Hospital in partnership with families of CMC to encourage families and providers to

Action Grid Packet

Patient Name: _____ **MR:** _____ **DOB:** _____
Provider: _____ **Date of Service:** _____
Parent/Caregiver Name: _____ **Preferred Contact Information (phone and/or email):** _____
Contact Information: _____ **If phone, best time to call:** _____
Phone: _____

Goals	Action	Who	When	Contingency
<i>Identify a short-term goal you would like to achieve for yourself, your child, or your family.</i>	<i>What needs to happen to reach this goal?</i>	<i>Who is responsible for completing this action?</i>	<i>What is the timeline that the action needs to be completed by?</i>	<i>If there is an issue or barrier, what are next steps?</i>

*For Families/Caregivers: Please focus on contributing ideas to section highlighted in blue (Patient Goals)

We want you to identify a short-term goal. Please read through the following list of ideas and think about something you would like to accomplish in the next few weeks. You will be able to discuss this worksheet and your goal with the APRN you are seeing today. Your short-term goal will be included in your discharge planning and clinic note.

Action Grid © 2017 Boston Children’s Hospital, Department of Accountable Care and Clinical Integration

discuss goals and identify actionable items during a patient encounter.²⁴ Permission to modify the tool to meet organizational requirements was obtained from the developers at Boston Children’s Hospital.

■ Intervention

An earlier goal-planning initiative for the inpatient care management program at the authors’ health system tested use of the Post-Encounter Action Grid for family identification of post-discharge goals.²⁵ Families found it difficult to articulate goals beyond leaving the hospital, and the authors recommended the use of prompts to help families think about broader goals.²⁵ Incorporating lessons learned from this pilot, the project leader worked with the organization’s parent advisors, care management team, and nurse researcher to develop example goals from six broad domains: activities of daily living, social services/financial, medical/health, family-centered, education, and environmental.²⁵ The modified Post-Encounter Action Grid and example goals were combined to create a goal-planning tool labeled the Action Grid Packet. Referred to in this manuscript as the packet, its purpose is to facilitate goal discussions and documentation between provider, patient, and family. The packet is a two-page, English-only, paper tool that is completed in partnership with the

NP. Goals, action, responsible person, a timeline for completion, and a contingency plan for barriers are documented on the first page. (See *Action Grid Packet*.) Example goals are listed on the second page. (See *Goal-planning examples*.) Reading level was not evaluated.

Following development, participating clinic team members (three NPs and five clinic nurses) received education that included packet purpose, intended use, EHR documentation, and how to introduce and explain the packet to families. The education occurred during a weekly staff meeting and in one-on-one sessions. The NP used best judgment to determine the amount of time allotted to discuss goals. Formal communication skills training was not provided for NPs as this is considered a key NP competency.

■ Implementation

The intervention was limited to patients being seen for their initial complex care clinic appointment with one of the three participating NPs. Non-English-speaking families were eligible if the interpreter working with the family was willing to translate the packet. The initial clinic visit was chosen for this project because the patient’s care plan and roadmap, which require goal discussion and planning, are developed during this visit. The NP facilitated goal planning by

encouraging the family to identify one or more goals, the action needed to complete the goal(s), the responsible person and timeline for completion, and a contingency plan in case of a barrier to completion. The NP documented this information using the packet. At the end of the clinic visit, a copy of the completed packet was given to the family and the original was stored in a locked clinic area for later use during

intervention evaluation. The NP included goals listed on the packet in the EHR clinic visit note. This process was chosen over scanning the handwritten packet into the EHR based on the pilot status of the intervention. Families that used the packet for goal identification were contacted 2 to 3 weeks after the clinic appointment by a nonclinical team member to assess goal completion, and additional assistance to achieve the goal was provided, if indicated.

Goal-planning examples

Activities of Daily Living

1. Arrange for extra support at home.
2. Start a resource list or internet library of reliable resources related to your child/young adult's diagnosis.

Social Services/Financial

1. Meet with county case manager or social worker. Ask for assistance and/or learn about your benefits.
2. Understand insurance, such as copays, deductibles, out-of-pocket expenses.
3. Find out how to become a paid patient care assistant.
4. Learn more about your family finances.

Medical/Health

1. Arrange for adequate supplies/equipment at home.
2. Make an appointment with primary care provider. Schedule vaccinations, such as influenza.
3. Make dental appointment.
4. Learn about your child/young adult's medications.
5. Keep a log/diary of your child/young adult's medical needs and history.
6. Establish patient portal access to Gillette and review your child/young adult's clinic notes and plan of care.
7. For non-English speakers, learn how to use the interpreter phone line to speak with Gillette staff.
8. Learn to change a gastrostomy tube or learn to catheterize your child/young adult.

Family Centered

1. Stay connected with important people in your child/young adult's life, such as grandparents, family, and friends.
2. Devote more time to siblings and spouse. Take time for yourself.
3. Pay attention to your own or your child/young adult's mental health and seek help if needed.
4. Voice your religious and spiritual beliefs.
5. Participate in a parent support group/network, such as Family Voices or Pacer.

Education

1. Meet with school or transition program staff/nurse. Discuss plan for education and support while in school. Discuss homeschooling.
2. Learn about individualized education programs and accommodations.

Environmental

1. Perform a safety evaluation of your home – check smoke/carbon monoxide detectors, change furnace filters, etc.
2. Take a CPR class.

Measures. Process measures and implementation fidelity as well as outcome measures determined packet usefulness. Implementation fidelity was defined as uptake of the intervention protocol by clinic staff and was measured by the number of patients who: were scheduled for an initial complex care clinic visit and eligible for the intervention; were given the intervention packet by the rooming clinic nurse; and had documented packet goals. Packet usefulness outcome measures were assessed for NP providers and families. For providers, usefulness was defined as inclusion of packet goals in formal visit documentation and measured as an agreement between goals documented on the packet and goals documented in the clinic visit note. For families, packet usefulness was defined as the ability to complete packet goals and measured by post clinic visit assessment of the number of packet goals achieved.

A project-specific, postintervention survey created by the project leader was completed by the three participating NPs. Personal opinions and insights about usefulness of the packet, individual experiences, recommendations for changes, and positive and negative aspects were solicited with open-ended questions. No psychometric reporting was conducted for this survey.

Analysis. Process and outcome measures were analyzed with descriptive statistics. Goals documented on the packet forms and responses from the postintervention survey were treated as qualitative data and analyzed using simplified content analysis. Content analysis is a qualitative research method for generating reliable and valid conclusions from text.²⁶ An iterative and inductive approach was conducted by the QI project lead, reading and categorizing the qualitative data to identify emergent themes.²⁷ No a priori themes were used.

Ethical considerations. Goal-planning discussions with families and corresponding documentation in the EHR are clinical expectations of this clinic's providers. The QI project was reviewed by the health system's Institutional Review Board and determined to not require human subject oversight.

■ Results

Consistent with PDSA cycles, modifications were made during implementation of the project based on feedback from clinic staff. Initially, the packet was given to families at clinic check-in for review in the clinic waiting room. Questions about the packet purpose and completion prompted revision of this process. The process was modified, and families received the packet from the rooming clinic nurse, along with direction to review the form prior to meeting the NP. During the 3-month intervention period, 30 patients were seen for their initial complex care clinic appointment by one of the participating NPs and were eligible for the QI intervention. Twenty-five (83%) of the eligible families received the packet during the clinic appointment. Five families did not receive the packet because of staff miscommunication regarding who would distribute it or family declining participation in the project. The average age of patients was 8.7 years (range 1 to 24 years). Two families were non-English-speaking. Of the 25 families that received the packet, 15 (60%) discussed and documented goals using the packet. Neither non-English-speaking family completed the packet due to difficulty by the interpreter translating the concepts. The remaining eight families did not complete the packet due to lack of time during the clinic visit.

Packet usefulness was determined from the 15 patients with handwritten goals on the saved packet. The NPs included the packet goals in eight (53%) EHR-documented clinic visit notes. Nine families (60%) indicated achievement of packet goals within 2 to 3 weeks of the clinic visit.

Themes that emerged from the qualitative inquiry provide contextual insight into implementation fidelity and packet usefulness findings. One theme reflected the overwhelming needs of the CMC population and their families and was identified in both data sources. For the NPs, the initial clinic visit focused primarily on assessment and evaluation of the child's complex medical and care coordination needs and consumed most of the 2-hour initial appointment. For some families, goal discussion was a new concept. Others felt unprepared to have goal discussions during the initial visit. Many focused on their child's physiologic needs during the 2-hour appointment, and this limited their ability to review, discuss, or complete the packet. These factors contributed to both NPs' and families' inability to use the packet as intended. They also

explain why only 15 of the 25 families that received the packet discussed and documented goals using the tool.

The subsequent plan of care developed by the NP at the initial clinic visit focused on goals that met the child's immediate health needs. The dominant theme of goals listed by families on the packet was their child's medical complexity with a focus on immediate and long-term medical concerns. Examples included obtaining an influenza vaccination, scheduling recommended appointments, keeping a sleep diary, doing more research related to a hereditary disorder, and changing a gastrostomy tube. Non-health-related goals, such as becoming more active as a family, speaking with a social worker, and developing coping skills, were expressed infrequently. Identification of long-term medical goals by families offers insight for why only 60% of families achieved their goals 2 to 3 weeks after their clinic visit.

The final theme providing context to findings was usefulness of the packet to NP workflow. Although the packet served as a helpful reminder for family goal discussions, NPs did not view it as a useful framework for documenting goals during the clinic visit or for later documentation in the clinic visit note. This could explain why only half of completed packet goals were listed in the clinic visit note. Equally important, clinic notes for patients whose families did not complete the packet had goals listed in their plan of care and reflected NP knowledge that goal discussions were best practice and critical for care coordination.

■ Discussion

This QI project implemented a family-centered goal-planning tool during a patient's initial visit to a pediatric complex care clinic. This was a significant system change because the initial clinic appointment focused primarily on evaluation of unmet medical needs and left little time for focused goal discussions. Findings revealed the challenges of implementing the goal-planning tool and provided insight into process modifications that would enhance usefulness and value of the tool.

Goal planning is foundational to family-centered care coordination and framing these discussions in the family perspective helps align family and clinical priorities.¹⁴ A newly implemented program identified a five-phase, multimonth approach to family-centered care coordination, with goal planning initiated at phase

four.¹² Earlier phases focused on relationship building with patient and family, which allowed success in later phases.¹² This project implemented goal planning before a relationship was established with mediocre success. This finding adds to the evidence regarding the importance of relationship building in family-centered care and has implications for practice.¹⁰ The authors recommend initiating family-centered goal planning at follow-up, not initial clinic visits, and including the clinic registered nurse care manager. The care manager is the families' primary contact for clinic visit follow-up and assistance between visits. Developing a relationship with the family is key to this role and involving the care manager in goal discussions would facilitate family-centered goal planning.

This project focused on CMC, but findings and lessons learned translate to other populations. The authors found families ill-prepared for goal-planning discussions, similar to families of hospitalized CMC who had difficulty identifying postdischarge goals.²⁵ Although the authors worked to mitigate this challenge with goal examples in various domains, the results did not improve. This differs from prior reports of successful goal planning with adult primary care patients and young adults with spina bifida.^{28,29} Unlike this project, these settings implemented goal planning after a relationship was established and demonstrated the value of the multiphase care coordination approach.^{12,28,29}

This QI project had limitations that could influence the findings and generalizability. This complex care clinic was established 18 months before project implementation. Patient volume increased rapidly during the project and clinic staff had difficulty adding new tasks such as the packet to their workflow. The packet was available in English only, and interpreters struggled to translate the information in the time provided. Finally, the packet was only piloted during initial clinic visits. It is unknown if the tool would have greater utility if used at follow-up clinic visits, but evidence suggests this possibility.

Conclusion

Optimal care for CMC includes patient- and family-centered goal planning, which can ultimately impact the Triple Aim by improving patient experiences, reducing cost, and improving overall population health.⁸ Family-centered goal discussions are a priority of the clinic team, but the initial appointment was not appropriate for these discussions. Goal-related discussions

should occur during subsequent follow-up appointments after a relationship is established, for maximum value. This key finding illustrates how value within the Triple Aim should be defined and measured. Value to the patient (achieve goals, stay healthy) and provider and care team (assess and maximize health) are often overshadowed by measures of value to the system (minimizing cost).³⁰ Process improvement and research initiatives for CMC must incorporate an understanding of what is valued by patients, their families, and their care team to address the lack of patient- and family-reported humanistic outcomes in CMC research.^{30,31} This project is a small step in recognizing both value and outcomes for patients, families, and providers. Future initiatives must continue this work. 

REFERENCES

- Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538.
- McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1 Pt 1):137-140.
- Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199-2206.
- Kuo DZ, Cohen E, Agrawal R, Berry JG, Casey PH. A national profile of caregiver challenges among more medically complex children with special health care needs. *Arch Pediatr Adolesc Med*. 2011;165(11):1020-1026.
- Allshouse C, Comeau M, Rodgers R, Wells N. Families of children with medical complexity: a view from the front lines. *Pediatrics*. 2018;141(suppl 3):S195-S201.
- Berwick DM, Nolan TW, Whittington J. The Triple Aim: Care, Health, And Cost. *Health Aff (Millwood)*. 2008;27(3):759-769.
- Institute for Healthcare Improvement. The IHI Triple Aim. 2019. www.ihio.org/Engage/Initiatives/TripleAim/Pages/default.aspx.
- Whittington JW, Nolan K, Lewis N, Torres T. Pursuing the Triple Aim: The First 7 Years. *Milbank Q*. 2015;93(2):263-300.
- Farrell T, Tomoiaia-Cotisel A, Scammon D, Day J, Day R, Magill M. Care Management: Implications for Medical Practice, Health Policy, and Health Services Research. (Prepared by Econometrica, Inc. under Contract No. HHS2902007 TO No. 5.) AHRQ Publication No. 15-0018-EF. Rockville, MD: Agency for Healthcare Research and Quality; 2015.
- Antonelli RC, McAllister JW, Popp J. Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. Commonwealth Fund; 2009. www.commonwealthfund.org/publications/fund-reports/2009/may/making-care-coordination-critical-component-pediatric-health.
- Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care coordination for children with medical complexity: whose care is it, anyway? *Pediatrics*. 2018;141(suppl 3):S224-S232.
- McAllister JW, Keehn RM, Rodgers R, Lock TM. Care coordination using a shared plan of care approach: from model to practice. *J Pediatr Nurs*. 2018;43:88-96.
- McAllister JW, McNally Keehn R, Rodgers R, Mpofu PB, Monahan PO, Lock TM. Effects of a care coordination intervention with children with neurodevelopmental disabilities and their families. *J Dev Behav Pediatr*. 2018;39(6):471-480.
- McAllister JW. *Achieving a Shared Plan of Care with Children and Youth with Special Health Care Needs*. Palo Alto, CA: Lucile Packard Foundation for Children's Health; 2014.
- Barnert ES, Collier RJ, Nelson BB, et al. Experts' perspectives toward a population health approach for children with medical complexity. *Acad Pediatr*. 2017;17(6):672-677.

16. Coller RJ, Berry JG, Kuo DZ, et al. Health system research priorities for children and youth with special health care needs. *Pediatrics*. 2020;145(3):e20190673.
17. Committee on the Learning Health Care System in America; Institute of Medicine. Engaging patients, families, and communities. In: Smith M, Saunders R, Stuckhardt L, McGinnis JM, eds. *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*. Washington, DC: National Academies Press; 2013:189-225.
18. Lindeke LL, Anderson SE, Chesney ML, O'Conner-Von S. Family-centered Health Care/Medical Home: APN Roles in Shaping New Care Models. *J Pediatr Health Care*. 2010;24(6):413-416.
19. NP Core Competencies Content Work Group. *NP Competencies - National Organization of Nurse Practitioner Faculties (NONPF)*. National Organization of Nurse Practitioner Faculties; 2017:16.
20. Cullen L, Hanrahan K, Farrington M, DeBerg J, Tucker S, Kleiber C. *Evidence-Based Practice in Action: Comprehensive Strategies, Tools, and Tips from the University of Iowa Hospitals and Clinics*. 1st ed. Indianapolis, IN: Sigma Theta Tau International; 2017.
21. Institute for Healthcare Improvement. Science of improvement: testing changes. 2020. www.ihp.org/resources/Pages/HowtoImprove/ScienceofImprovementTestingChanges.aspx.
22. Cady R, Bushaw A, Davis H, Mills J, Thomasson D. Care coordination for children with medical complexity. *Nurse Pract*. 2020;45(6):11-17.
23. Boston Children's Hospital. Multidisciplinary Care Planning. 2017. www.childrenshospital.org/integrated-care-program/multidisciplinary-care-planning.
24. Rosenberg H, personal communication. Sept. 25, 2017.
25. Antolick MM, Looman WS, Cady RG, Kubiawicz K. Identifying and communicating postdischarge goals for hospitalized children with medical complexity: a process improvement pilot in a specialty pediatric setting. *J Pediatr Health Care*. 2020;34(2):90-98.
26. Krippendorff K. *Content Analysis: An Introduction to its Methodology*. 3rd ed. Thousand Oaks, CA: Sage Publications; 2013.
27. Morse JM, Field PA. *Qualitative Research Methods for Health Professionals*. 2nd ed. Thousand Oaks, CA: Sage; 1995.
28. Handley M, MacGregor K, Schillinger D, Sharifi C, Wong S, Bodenheimer T. Using action plans to help primary care patients adopt healthy behaviors: a descriptive study. *J Am Board Fam Med*. 2006;19(3):224-231.
29. Seeley A, Lindeke L. Developing a transition care coordination program for youth with spina bifida. *J Pediatr Health Care*. 2017;31(6):627-633.
30. Nehal US, Maypole J, Sadof M. A patient-centered measure reduction strategy: three lenses of value. *Am J Med Qual*. 2018;33(6):665-667.
31. Looman WS, Park YS, Gallagher TT, Weinfurter EV. Outcomes research on children with medical complexity: a scoping review of gaps and opportunities. *Child Care Health Dev*. 2020;46(1):121-131.

Kathy Lindstrom is a DNP at Gillette Children's Specialty Healthcare Adult Outpatient Services, St. Paul, Minn.

Rhonda Cady is a nursing research specialist at Gillette Children's Specialty Healthcare, St. Paul, Minn.

Andrea Bushaw is a clinical practice specialist at Gillette Children's Specialty Healthcare, St. Paul, Minn.

The authors have disclosed no financial relationships related to this article.

DOI-10.1097/01.NPR.0000681796.57869.a0