

Figure 1. Conceptual Framework for Care Coordination/Fragmentation in the Context of the Patient-Centered Medical Home (PCMH) for Children with Complex Needs

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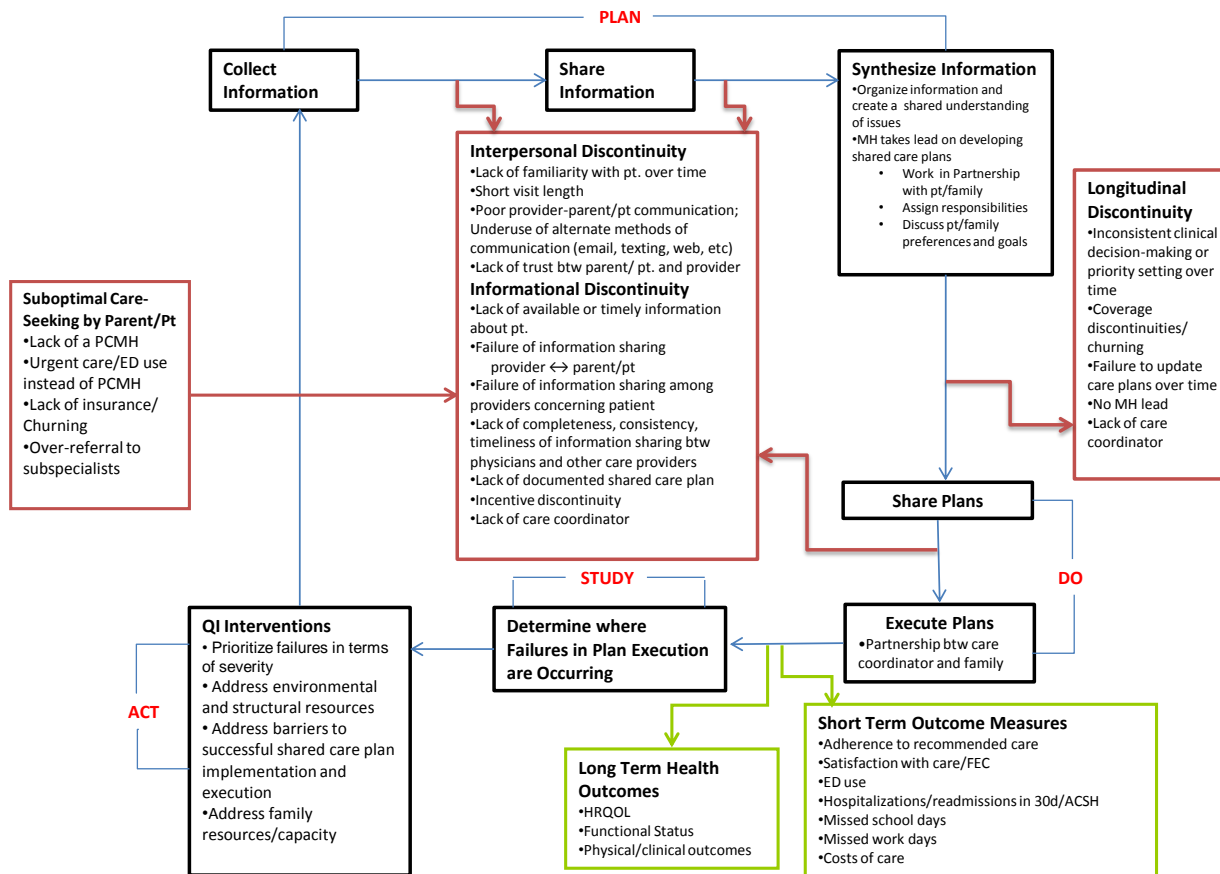


Table 2a: Proposed quality indicators for information exchange for children with medical complexity

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
FECC-9	Caregivers/patients of children with medical complexity (CMC) should report receiving a written visit summary following all outpatient visits in the last 6 months (or report access to a patient portal that provides a visit summary) and it should contain the following elements: <ul style="list-style-type: none"> a. current problem list b. current medication list c. drug allergies d. specialists involved in the child’s care e. planned follow-up 	2	Palfrey 2004 AAP 2005 NCQA 2011
FECC-10	Caregivers/patients of CMC who reported ever receiving a visit summary in the last 6 months (as identified in indicator 2) should report that the summary <ul style="list-style-type: none"> a. was easy to understand b. was useful 	5 5	AAP 2005 IOM 2001
FECC-11	Caregivers/patients of CMC should report having been invited to join in hospital rounds during their child’s last hospitalization	2a-3b (for caregiver participation) 5 (for patient participation)	Davidson 2007 (for caregiver participation, level of evidence is equivalent to 2a, 2b, 2c, 3a, or 3b; for patient participation with parental permission, level of evidence is 5)
FECC-12	Caregivers/patients of CMC should report receiving a written visit summary of their child’s hospitalization at discharge following all hospitalizations in the last 6 months (or report access to a patient portal that provides a hospitalization visit summary), and the summary should contain the following elements: <ul style="list-style-type: none"> a. problem list at time of discharge b. medication list at time of discharge c. drug allergies d. specialists involved in the child’s care during the hospitalization 	5	NCQA 2011 (extrapolated from outpatient standards)

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
	e. planned follow-up		
FECC-13	Caregivers/patients of CMC who received a visit summary of their child's hospitalization at discharge (as described in indicator 5) report that the information contained in the visit summary was easy to understand	5	NCQA 2011 (extrapolated from outpatient standards)

*Quality of Evidence Codes:

- 1: Randomized controlled trial (RCT)
- 2: Cohort studies
- 3: Case-control studies
- 4: Case-series
- 5: Consensus, opinions or "first principles" research

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Wharton ¹² Cross-sectional survey	Parents attending a conference sponsored by the Massachusetts Department of Public Health for parents of children with special needs (N=76)	Cross-sectional survey conducted at a conference	Yes												
Homer ¹³ Cross-sectional survey	Parents of children discharged from the hospital during specified months of 1991-1992 (N=3622)	Telephone survey of parents							↑ ¹						
Pabian ¹⁴ Cross-sectional survey	Families of children aged 0-3 years with disabilities (N=36 families). Disabilities was not defined, but most common diagnoses were developmental delays (53%), cerebral palsy (14%), premature infant (6%), and pervasive developmental disorder (6%)	Developmental evaluations of 36 children followed by telephone survey			↑										
Smaldone ¹⁵ Cross-sectional survey	New York State participants in the 2000–2002 National Survey of Children with Special Health Care Needs (N=748)	2000–2002 National Survey of Children with Special Health Care Needs			↑										

¹ Problems with information to parents correlated most strongly with parents' overall ratings of quality (r = 0.59), but no level of significance given

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Brown ¹⁶ RCT	Pediatricians (N=74) and their low-income patients/families (children aged 1-12 years with a diagnosis of asthma, no other chronic conditions, and had received emergency care for asthma at least once in preceding year) (N=279 with complete medical information and follow-up, out of 637 enrolled)	Interactive seminar with two components: optimal clinical practice based on National Asthma Education and Prevention Program Guidelines, and patient teaching and communication				↓	↓				↓				↓ ²
Cabana ¹⁷ RCT	Primary care providers (N=101) and a random sample of their asthma patients (children aged 2-12 years with no other disease associated with pulmonary complications such as tuberculosis, sickle cell disease, cystic fibrosis) (N=870)	Two interactive seminar sessions that reviewed national asthma guidelines, communication skills, and key educational messages				↓							↑		

² Low-income children in the treatment group tended to have higher levels of use of controller medications and to receive a written asthma action plan although these differences were not statistically significant.

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Clark ¹⁸ RCT	Pediatricians (N=74) and their asthma patients/families (children aged 1-12 years with a diagnosis of asthma, no other chronic conditions, and had received emergency care for asthma at least once in preceding year) (N=637)	Interactive seminar with two components: optimal clinical practice based on National Asthma Education and Prevention Program Guidelines, and patient teaching and communication				↓ ³	↓	nc							
Scal ¹⁹ Cross-sectional survey	Adolescents aged 14-17 years with special health care needs (N=4332)	2000-2001 National Survey of Children with Special Health Care Needs.										↑			

³ Decreased only if a high number of ED visits at baseline

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Palfrey ²⁰ Pre/post	Children ≤ 18 years old with special health care needs in 6 pediatric practices in Boston. (N=150) <i>Any 1 of:</i> ≥ 2 body systems involved, 1 body system involved, but severe, >3 hospitalizations/LOS >15 days, Medical technology dependent, Wheel chair dependent, Home-/school-based health services, High risk (<3 years old), Difficulty coordinating complex care	Integrated care (medical home) provided by a consortium of primary care and specialist providers		Yes		nc	←		↑	← ⁴	nc				
Lewis ²¹ RCT	English-speaking 6-17 year-olds accompanied by an adult who obtained health care from a study physician (N=141 patients). Physicians were pediatric trainees at 3 university-affiliated general pediatric practices.	Intervention was videotapes shown to parents, children, physicians; included promoting the child's development as an active participant in care.							↑ ⁵						↑ ⁶

⁴ Of note there was a small, nonsignificant decrement in satisfaction for a few items related to basic primary care services in the past 6 months (access to a provider for illness care, telephone advice, prescription refills, and access to referrals and specialized equipment and supplies).

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Rylance ²² Cross-sectional study	New and return pediatric outpatient consultations that were audiotaped (N=286)	Intervention was to audiotape visits, give copy to parents and then survey the parents							↑ ⁷						
Watkinson ²³ Cross-sectional study	Parents of infants with Down's syndrome (N=20 parents of 12 infants)	Audiotaped visits at which the parents were first given information about Down's syndrome, and then later surveyed parents for recall of information and satisfaction with recording							↑ ⁸						
Pitkethly ²⁴ Cochrane review	Systematic review of 16 controlled trials involving 2318 adult participants	Cochrane review of the effects of providing recordings or summaries of consultations to people with cancer and their families							↑ ⁹					nc ¹⁰	

⁵ Increase in child satisfaction only; no change in parent or physician satisfaction

⁶ Children in the intervention group recalled more medication recommendations

⁷ Audio tapes were helpful to 99% of parents

⁸ Most parents rated the audio tapes as "good" (6/20 parents) or "satisfactory" (13/20 parents)

⁹ Increased satisfaction (3/10 studies)

¹⁰ None of 3 studies showed change in quality of life , none of 10 studies showed change in anxiety or depression

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Murray ²⁵ Cochrane review (formal meta-analysis)	Articles pertaining to interactive health communication applications (IHCA) for people with chronic disease (N=24 RCTs)	Cochrane review to assess the effects of IHCA for people with chronic disease													↑ ¹¹
Liederman ²⁶ Cross-sectional survey	Healthcare providers at internal medicine, family practice, pediatric clinics and their patients/parents (N=826 patients enrolled in web messaging system)	Cross-sectional survey about web messaging system							↑						
Braner ²⁷ Cross-sectional study	Patients admitted to the PICU for ≥ 3 days and their families, as well as 25 physicians (N=73 pediatric patients)	Web-based link for PICU patients to serve both patient families and physicians; families could post messages to and from PICU RN and MDs.							↑						
Porter, 2006 ²⁸ RCT	English or Spanish speaking parents of children who were 1-12 years of age and had a respiratory complaint and history of asthma (N=286)	Asthma kiosk in ER for parents to report symptoms, medications, unmet needs.													↑ ¹²

¹¹ Also increased knowledge, social support, and health behaviors

¹² Providers did prescribe inhaled fluticasone to eligible patients more often during intervention than baseline; number of reported information problems was unchanged between the baseline and intervention periods. The mean number of partnership problems increased. Authors conclude that there was a small and variable effect on quality of care

Source and Study Design	Population	Program	Supports importance of receiving info	Supports importance of quality of info	Receipt of services	ED use	Hospitalization	OP visits	Satisfaction/perceived quality of care	Work Loss	School Absence	Transition of care	Function	Quality of life	Clinical outcomes
Porter, 2008 ²⁹ Quasi-experimental intervention study	Child-parent dyads presenting to 2 emergency department sites with complaints of fever, asthma, head trauma, otalgia, and dysuria were eligible (N=1410)	"ParentLink", a parent-driven health IT application that elicited the child's medication and allergy history and provided tailored prescribing advice.													nc ¹³

ED = Emergency department

OP = Outpatient

↑ = increase in any outcome measure within column domain

↑ = significant increase in any outcome measure within column domain

↓ = decrease in any outcome measure within column domain

↓ = significant decrease in any outcome measure within column domain

nc = no change

Yes = article does support the importance of receiving information or quality of information received

¹³ No impact on medication errors which was the outcome

Table 3a: Proposed quality indicators for aspects of care coordination for children with medical complexity

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
FECC-1	Caregivers of CMC should report that their child has a designated care coordinator.	2 2 1 2 2 5 2 4	Peters et al., 2011 ³⁰ Gordon et al., 2007 ³¹ Farmer et al., 2011 ³² Palfrey et al., 2004 ³³ Farmer et al., 2005 ³⁴ McAllister et al., 2009 ³⁵ Wood et al, 2008 ³⁶ Cady et al, 2009 ³⁷
FECC-2	Caregivers of CMC who report that their child has a designated care coordinator should report that they know how to access their care coordinator.	2 2 1 2 2 5 2 4	Peters et al., 2011 ³⁰ Gordon et al., 2007 ³¹ Farmer et al., 2011 ³² Palfrey et al., 2004 ³³ Farmer et al., 2005 ³⁴ McAllister et al., 2009 ³⁵ Wood et al, 2008 ³⁶ Cady et al, 2009 ³⁷
FECC-3	Caregivers of CMC who report having a designated care coordinator and who require community services should also report that their care coordinator helped their child to obtain needed community services in the last year.	2 1 4	Gordon et al, 2007 ³¹ Farmer et al. 2011 ³² Cady et al, 2009 ³⁷
FECC-4	Caregivers of CMC who report having a care coordinator should also report that their care coordinator has contacted them (via face-to-face contact, telephone, email, or written correspondence) or attempted to contact them at least once in the last 3 months.	2 1	Peters et al, 2011 ³⁰ Farmer et al. 2011 ³²
FECC-6	Caregivers of CMC who report having a care coordinator and who report that their care coordinator has contacted them in the last 3 months should also report that their care coordinator asked them about the following: a. caregiver concerns b. health changes of the child c. progress towards goals	2 1	Peters et al, 2011 ³⁰ Farmer et al. 2011 ³²
FECC-7	Caregivers of CMC who report having a care coordinator for their child should also report that	2 2	Peters et al, 2011 ³⁰ Gordon et al, 2007 ³¹

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
	<p>the care coordinator assists them with specialty service referrals by ensuring all of the following occur within 3 months of referral initiation:</p> <p>b2. the appointment with the specialty service provider occurs</p>	<p>1 2 4</p>	<p>Farmer et al. 2011³² Palfrey et al, 2004³³ Cady et al, 2009³⁷</p>
FECC-8	<p>Caregivers of CMC who report having a care coordinator should also report that their care coordinator:</p> <p>a. is knowledgeable about their child's health b. supports the caregiver c. advocates for the needs of their child</p>	<p>2 1 2 2</p>	<p>Gordon et al, 2007³¹ Farmer et al. 2011³² Palfrey et al, 2004³³ Farmer et al., 2005³⁴</p>

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Table 3b: Evidence table supporting links between proposed care coordination process measures and health outcomes

Source and Study Design	Population	Program	ED use	Hospitalization	Hospital bed days/LOS	OP visits	Cost of care	Written care plan	Work Loss	School Absence	Family Strain	Child health	Unmet needs	Satisfaction
Peter et al, 2011 ³⁰ Pre- and post-cohort	101 children complex care needs requiring care coordination and - >4 ED use or - >2 hospital admissions or - >14 days LOS in past year or infants at risk of future hospitalization	Tertiary pediatric hospital nurse care management and coordination in Australia	↓	↓	↓		↓							
Gordon et al, 2007 ³¹ Pre- and post-cohort	227 children Required both major complexity and fragility criteria OR multiple minor criteria <u>Complex:</u> <i>Major:</i> ≥ 3 organ systems AND ≥ 5 specialists <i>Minor:</i> Multiple factors of: Disease uncertain/unknown, PCP did not admit to study hospital, major socioeconomic factors, lives >25 miles from study hospital <u>Fragile:</u> <i>Major:</i> ≥ 2 admissions in past year AND ≥ 10 hospital days/clinic visits <i>Minor:</i> Multiple factors of: ≥ 1 admission, ≥ 5 hospital days/clinic visits in past year, anticipated frequent use based on disease trajectory, technology dependence/home nursing	Tertiary pediatric hospital 2 tiered program with 70% of patients assigned to nurse care manager only and 30% to nurse care manager and physician partner.	↑	↓	↓	↑	↓							

Source and Study Design	Population	Program	ED use	Hospitalization	Hospital bed days/LOS	OP visits	Cost of care	Written care plan	Work Loss	School Absence	Family Strain	Child health	Unmet needs	Satisfaction
Farmer et al. 2011 ³² RCT	70 Children - enrolled in Medicaid managed care - residing in service area - has a chronic health condition expected to last for at least 12 months with at least 1 positive indicator in the CSHCN Screener and < 18 years of age	Nurse or social worker care coordinator assigned to 93 primary care practices.						↑			←	↑	←	↑
Palfrey et al, 2004 ³³ Pre- and post-cohort	117 children ≤ 18 years old <i>Any 1 of:</i> - ≥ 2 body systems involved, - 1 body system involved, but severe, - >3 hospitalizations/LOS >15 days, - Medical technology dependent, - Wheel chair dependent, - Home-/school-based health services, - High risk (<3 years old), Difficulty coordinating complex care	Integrated care (medical home) provided by a consortium of primary care and specialist providers Nurse for care coordination	nc	↓				↑	↓	nc				↑
Farmer et al., 2005 ³⁴ Pre- and post-cohort	51 Children with complex chronic condition expected to last >12 months AND at least one of the following - Biologically based health problem involving >1 body system or severe single system that interfered with everyday functioning - Ongoing involvement with multiple medical specialists - >3 hospitalizations within previous year or hospitalization >15 days - Dependence on technology or wheelchair - Ongoing need for home or school based services Difficulty coordinating care as a result of complexity of child's problems	Nurse led care coordination consultation to 3 practices						nc	↓				↓	↑

Source and Study Design	Population	Program	ED use	Hospitalization	Hospital bed days/LOS	OP visits	Cost of care	Written care plan	Work Loss	School Absence	Family Strain	Child health	Unmet needs	Satisfaction
McAlister, Sherrieb, Cooley, 2009 ³⁵ evaluation of demonstration project Pre/post comparison	82 Children with special health care needs	Ten practices participate in a medical home improvement process		↓	↓	↓		↑		↓	↓			
Wood et al, 2008 ³⁶ Practice based intervention with prospective comparison cohort	144 children Children enrolled in Title V	Compared nurse led practice based care coordination (intervention) in 3 practices with Title 5 agency based care coordination (control) in 3 practices											↓	↑
Cady et al, 2009 ³⁷ retrospective record review	43 children > 4 significant chronic medical problems - multiple medical specialists - multiple medications - repeated hospitalizations and/or ED visits - dependence on technology needs not being met by another service	Nurse led telephone based comprehensive care coordination		↓										

Arrows in bold represent statistically significant findings.

ED = Emergency department

LOS=Length of stay

OP = Outpatient

↑ = increase in any outcome measure within column domain

↓ = decrease in any outcome measure within column domain

nc = no change

Table 4a: Proposed quality indicators for shared care plans

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
FECC-16	<p>Caregivers of CMC should report the following:</p> <p>a. the child’s primary provider created a shared care plan for their child</p> <p>b. the caregiver participated in developing the written shared care plan*</p> <p>c. the caregiver participated in updating their child’s written shared care plan with their child’s primary care provider in the previous year*</p> <p>d. the caregiver received a copy of the shared care plan*</p>	<p>5</p> <p>4</p> <p>2</p> <p>1</p>	<p>AAP 2002 and 2005³⁸</p> <p>Gordon,³⁹ Farmer,⁴⁰ Palfrey,²⁰ Casey,⁴¹ Cady,³⁷ Chen,⁴² Weiland,⁴³ Rocco⁴⁴</p> <p>Farmer,⁴⁵ Dorr⁴⁶</p> <p>Counsell,⁴⁷ Lozano,⁴⁸ Unutzer,⁴⁹ Katon,⁵⁰ Katon,⁵¹ Aiken⁵²</p>
FECC-18	<p>Caregivers of CMC who are age 15 years or older, should report the following:</p> <p>a. the child’s primary provider created a written transition plan for their child</p> <p>b. the caregiver participated in developing a written plan for transitioning pediatric medical services over to adult medical services*</p> <p>c. the caregiver participated in updating their child’s written transition plan in the previous year*</p> <p>d. the caregiver received a copy of the written plan for transition*</p>	<p>5</p> <p>4</p>	<p>AAP 2002^{53,54}</p> <p>Kelly⁵⁵</p>
FECC-17	<p>Caregivers of CMC should report the following:</p> <p>a. the child’s primary provider created an</p>	<p>5</p>	<p>AAP 2010⁵⁶</p>

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
	<p>emergency care plan for their child</p> <p>b. the caregiver participated in developing the written emergency care plan^a</p> <p>c. the caregiver participated in updating their child's written emergency care plan with their child's primary care provider in the previous year^a</p> <p>d. the caregiver received a copy of the emergency care plan^a</p>		
SCP7	<p>Caregivers of CMC who report that they have an emergency care plan for their child should also report that it includes all of the following:^a</p> <ul style="list-style-type: none"> (a) a list of medical problems or diagnoses;^a (b) a list of current medications and medication allergies;^a (c) their primary care provider's contact information^a (d) special considerations for their child (e.g. usual signs suggesting the child is in pain, the child's baseline mental status, etc)^a 	5	AAP 2010 ⁵⁶

^aThese indicators were dropped from the survey following field testing due to low numbers of eligible children and/or ceiling effects

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Table 4b: Summary of reviewed studies providing evidence for outcomes associated with shared care plans

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
AAP 2002; The Medical Home ³⁸ Policy statement	All children with the medical home	Medical home should include: collaboration to establish shared care plan (parent, PCP, subspecialists), care coordination to implement plan													
AAP 2002; Health care Transitions ⁵³ Consensus statement	Young adults with special health care needs	Tertiary pediatric hospital 2 tiered program with 70% of patients assigned to nurse care manager only and 30% to nurse care manager and physician partner.													
AAP 2005; Care Coordination in the Medical Home ¹ Policy statement	Children with special health care needs receiving care coordination within the medical home	Builds on 2002 statement and reiterates: “ plan of care is developed by the physician, practice care coordinator, child, and family in collaboration with other providers...”													
AAP 2010: Emergency Information Forms ⁵⁶ Policy statement	Children with special health care needs within the medical home	Emergency Information Form should be initiated by medical home, include input from specialists, be updated regularly, and serve as a concise patient summary													
Adam, ⁵⁷ 2010 Controlled intervention, non-randomized	20 adult outpatients with chronic, complex illness (12 intervention, 8 control)	Shared care plan: “Care Team” care, in which the team of 4 doctors, a psychologist, a pharmacist and a nurse discuss the patient and develop a tentative plan; the plan is discussed with the patient, their feedback is incorporated, and then the plan is implemented	↑	nc	↓					↑					

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Aiken, ⁵² 2006 RCT	192 adults with COPD or CHF and estimated 2 year life expectancy; 101 assigned to intervention	Care coordination: A nurse case manager, supported by a medical director, social worker, and pastor, provided in-home and telephone support, education, and care plan development to patients. The care plan was shared with the PCP and other service providers.	nc									↑			↑
Cady, ³⁷ 2009 Uncontrolled intervention	43 children with complex chronic disease	Care coordination: Nurse practitioners provided phone-based care coordination between the family, PCP, and specialists, and helped develop a medical management plan for recurrent acute illnesses (intervention details from Kelly et al.)		↓											
Casey, ⁴¹ 2011 Uncontrolled intervention	225 children with complex chronic disease	Care coordination: Multidisciplinary clinic (MD, RN, nutrition, social work) worked with the family to develop an Individual Health Plan, which included a medical summary, medications list, and therapeutic plans of care. They also helped to coordinate care between providers and services.		↓	↑	↓									

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Chen, ⁴² 2000 Non-systematic review	29 care coordination programs for adults with chronic systemic disease	Care coordination: Reviewed care coordination programs associated with demonstrated decreases in hospitalizations or health care expenditures; also reviewed selected programs with no demonstrated impact on cost or hospitalizations for comparison. Developing a written, goal-oriented, individualized care plan was found to be a common element in programs with a cost-saving impact. All programs had a coordinator responsible for assessing client progress and adjusting plan as needed, with widely variable time intervals. Programs that included typical components but had no measured impact (n=5) had less comprehensive, less specific, and less goal-oriented care plans. Two of those programs also had inflexible reassessment schedules, not allowing as-needed retooling of the plan.		↓		↓									
Counsell, ⁴⁷ 2007 Cluster RCT	951 low income seniors with chronic illness, 474 randomized to intervention	Care coordination: Two years of home-based care management by a nurse practitioner and social worker, collaborating with the PCP and an interdisciplinary team to develop and implement an individualized care plan with annual reassessment	↓	↓						↑	nc	↑		nc	

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Dorr, ⁴⁶ 2008 Controlled intervention, non-randomized	3432 chronically ill adults >64 years , 1144 in the intervention	Care coordination: Patients from intervention clinics were referred by their PCPs to the intervention, which consisted of a nurse care manager using structured protocols and flexible, patient-specific shared care plans. Intervention patients were matched to 2 patients from control clinics on age, comorbid score, sex, specific diseases, recent hospitalizations, and hospice; these patients received usual care.	↑	↓										95↓	
Farmer, ⁴⁵ 2011 RCT with crossover to intervention	100 children with chronic illness on Medicaid; 50 randomized to each arm, 36 intervention and 25 controls completed	Care coordination: 6 month intervention supporting 32 PCP offices, in which the care coordinator worked with the family to develop a written health plan for the child, provide access to services, coordination with doctors and home visit/ telephone support						nc	nc		↑		↑		
Farmer, ⁴⁰ 2005 Uncontrolled intervention	51 children with complex chronic disease	Care coordination: Nurse practitioner-led care coordination involving a home visit, assessment, referral to resources, and an individualized written plan with specific goals. The NP serves as a consultant to the PCPs			↓			↓	↓	↓		↑	↑		

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Gordon, ³⁹ 2007 Uncontrolled intervention	227 complex chronic fragile children	Care coordination: Depending on complexity and number of involved providers, patients were assigned to an NP only or NP and MD, who developed a care plan with the family, interfaced with the PCP along with other providers and services, and provided support	↑	↓	↑	↓									
Katon, ⁵¹ 2010 RCT	214 adults with poorly controlled DM, CHD, or both and depression; 106 randomized to the intervention	Disease management/ Care coordination: 12 month intervention in which a nurse care coordinator, supervised by a psychiatrist, the PCP, and a psychologist, worked with patients to develop and implement an individualized treatment plan.								↑		↑	↑		
Katon, ⁵⁰ 2001 RCT	386 adults with major depression, currently controlled; 194 randomized to the intervention	Disease management: Intervention included 2 visits with a depression specialist in which a written personal relapse prevention plan was devised and then shared with the PCP, 3 follow up phone calls, and medication refill monitoring.					↑			↑/nc					
Kelly, ⁵⁵ 2002 Case series	2 adolescents in the U Special Kids program with complex chronic conditions	Care coordination: Collaborative development of a medical summary and individualized care plan, including input from parents, PCP, specialists, nurses										↑	↑		

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Lozano, ⁴⁸ 2004 Multisite cluster RCT	678 children with mild to moderate persistent asthma; 199 allocated to control, 226 to a peer leader intervention, and 213 to a care planning intervention; 13% drop out	Disease management: Asthma nurses conducted assessment, developed individualized care plan with family, provided self-management support and phone follow up There was also an MD peer leader to champion office-wide change								↑	nc				
Palfrey, ²⁰ 2004 Uncontrolled intervention	117 children with complex and/or chronic medical conditions in 6 practices	Care coordination: A nurse practitioner serving as care coordinator within a medical home model provided home visits (including sick visits), family support, and services coordination, as well as working with the family to develop a written care plan	nc	↓				↓	nc				↑		
Rocco, ⁴⁴ 2011 Controlled retrospective cohort	1110 adults with chronic disease (at least one of: DM, CAD, HTN, heart failure); 593 patients enrolled in the intervention	Shared care plan/ Care coordination: Plan of care intervention, in which PCP and patient collaborate to develop individual problems, goals, and actions to be taken, within a medical home model clinic; controls were drawn from a non-medical home model clinic without the plan of care tool.								↑					
Unutzer, ⁴⁹ 2002 RCT	1801 adults >59 years old with major depression or dysthymic disorder; 906 randomized to the intervention	Disease management: Intervention included 12 months of depression care management by a care manager, under the supervision of an internist and a psychiatrist, beginning with assessment and development of an individualized care plan guided by algorithms					↑			↑	↑	↑	↑		

Source and Study Design	Population	Intervention	ED use	Hospitalization ^a	OP visits	Cost of care	Compliance	Work Loss	School Absence	Clinical measures	Function	Quality of life	Satisfaction ^b	Mortality	Knowledge
Weiland, ⁴³ 2003 Intervention with non-comparable controls	22 adolescents with CF; 17 enrolled in the intervention	Disease management: The intervention consisted of an individualized daily inpatient schedule that the adolescent developed with care team. The control group was made up of patients who declined to participate in the intervention.											↑		

Legend: ED = Emergency department

OP = Outpatient

↑ = Increase in any outcome measure within column domain (bold indicates statistically significant)

↓ = Decrease in any outcome measure within column domain (bold indicates statistically significant)

nc = No change

^aThis category includes number of hospital days, number of hospitalizations, and number of unplanned hospitalizations; see review text for details

^bMultiple different measures of satisfaction were used within and between studies; see review text for details. A positive indicator in this column reflects improvement in any measure of satisfaction.

^cNo statistical testing performed

^dAs measured by symptom-related distress

^eThese outcomes were selected as a condition for inclusion in the review

^fIn the patient subgroup classified prior to intervention as being at high risk for hospitalization

^gIn the patient subgroup with diabetes mellitus

^hAt the end of year 1 (but not year 2) for the overall study population

ⁱIn the more complex subgroup assigned to the NP/MD team

^jIntervention patients reported fewer depressive symptoms but had depression relapse rates that did not significantly differ from those of controls

Table 5a: Proposed indicators for medical home

Number	Quality Indicator	Quality of Evidence*	Supporting Literature
FECC-19	Caregivers of CMC should report having access to a personal health record that includes the following health information:	4	Palfrey, 2004 ²⁰ AAP, 2011 ⁵⁸
	<ul style="list-style-type: none"> a. Immunization record b. Medications <ul style="list-style-type: none"> i. which are up-to-date^a ii. which include dosages^a 	5	
FECC-14	Caregivers of CMC should report that one of their child's health care providers (i.e., primary care physician, specialist physician, care coordinator, NP, nurse, social worker, etc) communicated with school staff at least once a year about the educational impacts of the child's condition.	5	Savage, 2001 ⁵⁹
FECC-15	Caregivers of CMC or CMC who self-identify as having a preference for conducting medical visits in a language other than English should have access to a professional medical interpreter (live or telephonic) at all visits for which an interpreter is needed.	2	Raphael et al., 2009 ⁶⁰

^aThese indicators were dropped from the survey following field testing due to low numbers of eligible children and/or ceiling effects

*Quality of Evidence Codes:

- 1: Randomized controlled trial (RCT)
- 2: Cohort studies
- 3: Case-control studies
- 4: Case-series
- 5: Consensus, opinions or "first principles" research

Table 5b: Evidence supporting links between medical home process measures and health outcomes

Source and Study Design	Population	Intervention/ Program/ Predictor Variable	ED use	Hospitalization	Work Loss	School Absence	Family Involvement in Decision Making	Use of Written Care Plans	Satisfaction	Therapeutic Unmet Needs	Supportive Unmet Needs	Family Functioning	Child Functioning	Need for OT/PT/Speech	Medical Home Components
AAP, 2011 ⁵⁸ Policy statement	Children within the medical home	Recommend the “development and universal implementation of a comprehensive electronic infrastructure to support pediatric information functions of the PCMH”													
Savage, 2001 ⁵⁹ Guideline	Children with traumatic brain injury	Provide recommendation for transitioning back to school, including communication between school and medical home													
Palfrey ²⁰ Pre-post	≤ 18 years old Any 1 of: ≥ 2 body systems involved, 1 body system involved, but severe, >3 hospitalizations/LOS >15 days, Medical technology dependent, Wheel chair dependent, Home-/school-based health services, High risk (<3 years old), Difficulty coordinating complex care N = 150	Integrated care (medical home) including, a) services of a pediatric nurse practitioner to complete home visits to assess needs and resources and help with care coordination, b) development of an Individualized Health Plan to share information across providers and settings, and c) outreach and social activities to provide support to families.	nc	↓	↓	nc			↑	↓ 14	↓				

Source and Study Design	Population	Intervention/ Program/ Predictor Variable	ED use	Hospitalization	Work Loss	School Absence	Family Involvement in Decision Making	Use of Written Care Plans	Satisfaction	Therapeutic Unmet Needs	Supportive Unmet Needs	Family Functioning	Child Functioning	Need for OT/PT/Speech	Medical Home Components
Nijhuis ⁶¹ Descriptive	38 parents of children with cerebral palsy, ages 4 – 8, a member of the rehab team and a member of the special education team	Parent perceptions of family-centered care					↑	↑							
Farmer ⁴⁵ RCT	>18, enrolled in Medicaid, living in the 16-county service area, at least 1 positive indicator on the CSHCN screener N = 100	Consultative care coordination							↑	↓		↑	↑		
Gfroerer ⁶² Descriptive	Parents of children having received care in a medical center within the previous 2 years, with evidence of brain injury on neuroimaging, with severe impairment (Glasgow Coma Scale 3-8) N = 66	Parent perceptions of school-based support for students w/TBI												↑	

Source and Study Design	Population	Intervention/ Program/ Predictor Variable	ED use	Hospitalization	Work Loss	School Absence	Family Involvement in Decision Making	Use of Written Care Plans	Satisfaction	Therapeutic Unmet Needs	Supportive Unmet Needs	Family Functioning	Child Functioning	Need for OT/PT/Speech	Medical Home Components
Raphael ⁶⁰ Outcomes	Families with children <18 years across the U.S., low income and/or racial/ethnic minority (compared to white respondents) N = 102,353	Having a medical home including, having providers who spent enough time with them, communicated well, provided care or advice over the phone, getting care right away, and access to specialty care, services, and equipment.													←

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