



**Commonwealth of Kentucky
Department for Medicaid Services
Division of Program Quality and Outcomes**

Kentucky Medically Fragile Children Focused Study

FINAL REPORT
August 2015

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Introduction

Hospitalization rates for medically complex children are increasing in the United States (Burns *et al.*, 2010) and care coordination has been shown to significantly decrease the number of hospital days and hospitalizations among medically complex and fragile children and youth (Gordon *et al.*, 2007). Disparities between publicly vs. privately insured children in Kentucky suggest opportunities for improvement. For example, data from the 2009/2010 National Survey of Children with Special Health Care Needs found that, in Kentucky, only 56.3% of publicly insured children with special health care needs (CSHCN) who needed care coordination received effective care coordination, whereas a greater percentage (68.7%) of privately insured CSHCN who needed care coordination received effective care coordination (CAHMI, 2012). Effective care coordination was defined as receiving help with coordination of care and satisfaction with communication among providers (CAHMI, 2012).

Children in foster care are more likely to have chronic health problems and special health care needs (Ringeisen *et al.*, 2008); therefore, effective care coordination is especially important for this vulnerable subpopulation. Yet, the 2014 Kentucky External Quality Review Organization (EQRO) Managed Care Organization (MCO) Annual Compliance Review found variability among Medicaid MCOs' compliance with contract requirements for collaboration with the Department for Community Based Services (DCBS) to determine the foster child's medical needs, identify the need for case management, and conduct ongoing care coordination (Island Peer Review Organization; IPRO, 2014). The Kentucky Commission for Children with Special Health Care Needs (CCSHCN) provides nursing consultative services to DCBS for medically fragile children in the foster care system. The CCSHCN nurse consultant works to "enhance care coordination of all services" (Kentucky CCSHCN, 2014); however, it is unclear how MCO care managers, DCBS social workers, and CCSHCN nurse consultants work together towards this common objective.

Relational coordination (RC) is the process of interaction between communication and relationships conducted for achievement of a desired outcome (Gittel, 2012) and, among health care service users with complex medical needs, the pattern of interaction between case managers and their co-workers was the most influential factor on the quality of care coordination (McEvoy *et al.*, 2011). Decreased length of hospital stay has been associated with coordination of care for medically complex and fragile children (Gordon *et al.*, 2007), as well as with RC for adult surgical patients (Gittel *et al.*, 2000). Therefore, enhanced care coordination and, more specifically, relational care coordination, may

potentially reduce the number of hospital days for medically fragile children placed in foster care and enrolled in Kentucky Medicaid managed care (MMC). The Relational Coordination Survey (RC Survey) is an Agency for Healthcare Research and Quality (AHRQ) endorsed care coordination measure used to “determine the impact of RC on quality of care by measuring dimensions of communication and relationships among health care providers” (AHRQ, 2014).

Study Goal, Aims and Objectives

The overarching goal of the Kentucky Medically Fragile Children Focused Study was to improve the quality of care coordination for MMC enrollees aged 0–20 years who have complex health care needs and are in foster care.

The study aims were two-fold:

- I. Profile health care utilization among medically fragile children in foster care who are enrolled in Kentucky MMC:
 - a. Profile demographics (e.g., age, sex, race/ethnicity, eligibility category, urban/rural residence) and clinical characteristics (e.g., complex chronic conditions [CCCs]) of medically fragile children who were enrolled in MMC and were in foster care. Incorporate care/case management record review findings for the subsample of medically fragile children with at least six months of active medically fragile status designation during July 1, 2013 through June 30, 2014, in order to profile level of technology dependence.
 - b. Profile health care utilization for medically fragile children who were enrolled in MMC and were in foster care overall, as well as by MCO, including metrics such as the total number of hospitalizations, number of hospital days, number of emergency department (ED) visits, number of outpatient primary care provider (PCP) visits, number of outpatient specialty visits, number of dental visits, and the number of home care visits.
 - c. Evaluate the quantity of hospital utilization among medically fragile children relative to children who were not designated as medically fragile. Compare the number of hospital days and number of ED visits per child, among all medically fragile children, all other children in foster care, and all other children enrolled in MMC.

- d. Identify other high-risk children in foster care with chronic (one or more CCCs) and unstable (repeat hospitalizations and ED visits) conditions for consideration as possibly “missed” medically fragile children.
 - e. Profile pre-authorization and claims denials by MCO for the subsample of medically fragile children who were enrolled in MMC, were in foster care, and had at least six months of active medically fragile status designation through June 30, 2014, in order to identify denial patterns for follow-up.
- II. Identify gaps in care coordination for medically fragile children and opportunities to improve the performance of the care coordination team that consists of MCO care/case managers, DCBS social workers, and CCSHCN nurse consultants:
- a. Conduct and summarize results from the RC Survey of the medically fragile care coordination team.
 - b. Quantify care/case management record descriptive statistics regarding MCO care management interventions, overall and by MCO, for the subsample of medically fragile children who were enrolled in MMC, were in foster care, and had at least six months of active medically fragile status designation from July 1, 2013 through June 30, 2014.
 - c. Quantify case management record descriptive statistics regarding DCBS care management interventions, overall and by DCBS region, for the subsample of medically fragile children who were enrolled in MMC, were in foster care, and had at least six months of active medically fragile status designation from July 1, 2013 through June 30, 2014.
 - d. Quantify case management record descriptive statistics regarding CCSHCN care management interventions, overall and by DCBS region, for the subsample of medically fragile children who were enrolled in MMC, were in foster care, and had at least six months of active medically fragile status designation from July 1, 2013 through June 30, 2014.
 - e. Quantify and compare MCO, DCBS and CCSHCN nurse consultant care management documentation for the subsample of medically fragile children who were enrolled in MMC, were in foster care, and had at least six months of active medically fragile status designation from July 1, 2013 through June 30, 2014.
 - f. Qualitatively integrate results from the RC Survey, care/case record and denials reviews.

Methodology

Data Sources and Samples

Medically Fragile Children

The Kentucky Department for Medicaid Services (DMS) provided IPRO a list of children who were designated by the DCBS Medical Support Section as medically fragile and enrolled in MMC during the period from July 1, 2013 to June 30, 2014. This list was used to identify the overall medically fragile children sample (n = 223). Demographic, health care utilization and diagnosis data for these children were obtained from electronic encounter files for the period from July 1, 2013 to June 30, 2014 for comparison with all MCO enrollees of the same age range (0–20 years; sample size “n” = 617,703), children in foster care who were not medically fragile (n = 10,869), and all children who were not medically fragile (n = 617,480). An additional subset was comprised of children in foster care with at least one CCC (**Appendix A**; Feudtner *et al.*, 2000) and the following indicators of unstable health status: two or more ED visits and two or more hospitalizations (n = 82). This subset of high-risk children in foster care (i.e., with at least one CCC and unstable health status) was further subset into children designated as medically fragile (n = 25) and not designated as medically fragile (n = 57) in order to assess possible gaps in the identification of medically fragile children in foster care.

The list of medically fragile children was also used to identify the duration of medically fragile status as defined by the difference between DMS-provided fields for “approval date” and “release date.” A subsample of 111 medically fragile enrollees with at least six months duration of medically fragile status during July 1, 2013–June 30, 2014 was selected for a review of care/case management charts obtained from MCOs, CSHCN and DCBS. The final chart review subsample was comprised of 105 enrollees after exclusion of 6 children identified by the plans as non-MCO members. There were 21 children in the medically fragile chart review subsample identified by the MCOs as having one or more service denials, and the utilization management records (e.g., notification letters of service denial) for these children were reviewed to assess patterns of denials.

Care Coordinators of Medically Fragile Children

DMS provided IPRO a list of DCBS and CSHCN case managers and care coordinators who work with medically fragile children, and IPRO obtained a list of MCO care/case managers who work with this same population from the Kentucky MCOs. A total of 168 DCBS, 18 CSHCN and 26 MCO care coordinators were invited to participate in the RC Survey, and there were 89 (53%), 17 (94%) and 18

(69%) survey participants, respectively, in the final sample of care coordinators who work with medically fragile children. IPRO subcontracted with Relational Coordination Analytics (Cambridge, MA) to conduct and analyze the RC Survey of all care coordination team providers who care for medically fragile children, who were in foster care and were enrolled in MMC.

Data Analysis and Statistical Methods

Member demographic, utilization and clinical data were summarized using frequencies and proportions. Differences in mean hospitalizations, total hospital days, number of ED visits and number of PCP visits were tested for statistical significance using the *t* test with $P < 0.05$, for comparisons between medically fragile children and children who were not medically fragile in foster care, and between medically fragile children and all children who were not medically fragile.

Relational Coordination Analytics analyzed overall RC Survey findings, and IPRO conducted drill down analyses by workgroup, as well as analyzed custom question responses. IPRO drilldown findings by workgroup depicted mean ratings using bar charts. The *chi*-square statistic was used to identify statistically significant differences (i.e., $P < 0.05$) in proportions among workgroups for the custom questions asked of all survey participants. Case management/care coordination and denial review findings were summarized using frequencies and proportions. RC Survey findings were integrated with care/case management review and utilization management findings by qualitatively interpreting results in the **Discussion** section of the report.

Results

Demographic and Clinical Characteristics of Medically Fragile Children in Foster Care

The majority of foster care children designated as medically fragile were between the ages of 1 and 5 (36%), followed by children 13–20 years of age (26%), those of age less than 1 year (24%) and those 6–12 years of age (14%; **Table 1**). The race/ethnicity of a large proportion (29%) of these children was not provided; however, the remaining 71% (158/223) were designated as white (101/223 = 45%; 101/158 = 64%), other (37/223 = 17%; 37/158 = 23%) or black (20/223 = 9%; 20/158 = 13%). There were slightly more males (57%) than females (43%), and more urban dwellers (56%) than rural dwellers (44%).

Thirty-eight percent (38%) of medically fragile children did not have any CCCs, 28% had one and 35% had two or more (**Table 1**). Cardiac conditions comprised the highest percentage of CCCs (27%), followed by hereditary immune deficiency (19%), infantile cerebral palsy (11%), brain/spinal cord anomaly (10%), and congenital bone anomaly (9%). Cardiac conditions consisted of an aggregate grouping of four cardiovascular conditions (**Appendix A**). The most prevalent specific diagnoses included esophageal reflux (23%), seizures/epilepsy (22%), asthma (20%), failure to thrive (19%) and diabetes (17%).

Table 1. Demographic and Clinical Characteristics of Medically Fragile Children in Foster Care

Characteristics	Overall ¹ n = 223 # (Column %)	CoventryCares of Kentucky n = 77 # (Row %) (Column %)	Humana- CareSource n = 5 # (Row %) (Column %)	Passport Health Plan n = 30 # (Row %) (Column %)	WellCare of Kentucky n = 111 # (Row %) (Column %)
Demographic characteristics (source: administrative/claims files; n = 223)					
Age group					
< 1 year	53 (24%)	19 (36%) (25%)	3 (6%) (60%)	8 (15%) (27%)	23 (43%) (21%)
1–5 years	81 (36%)	25 (31%) (32%)	2 (2%) (40%)	8 (10%) (27%)	46 (57%) (41%)
6–12 years	31 (14%)	13 (42%) (17%)		4 (13%) (13%)	14 (45%) (13%)
13–20 years	58 (26%)	20 (34%) (26%)		10 (17%) (33%)	28 (48%) (25%)
Race/Ethnicity					
White	101 (45%)	40 (40%) (52%)		10 (10%) (33%)	51 (50%) (46%)
Black	20 (9%)	7 (35%) (9%)	2 (10%) (40%)	9 (45%) (30%)	2 (10%) (2%)
Other	37 (17%)	10 (27%) (13%)	1 (3%) (20%)	3 (8%) (10%)	23 (62%) (21%)
Not provided	65 (29%)	20 (31%) (26%)	2 (3%) (40%)	8 (12%) (27%)	35 (54%) (32%)
Sex					
Male	128 (57%)	44 (34%) (57%)	4 (3%) (80%)	16 (13%) (53%)	64 (50%) (58%)
Female	95 (43%)	33 (35%) (43%)	1 (1%) (20%)	14 (15%) (47%)	47 (49%) (42%)
Residence type					
Urban	124 (56%)	38 (31%) (49%)	5 (4%) (100%)	26 (21%) (87%)	55 (44%) (50%)
Rural	99 (44%)	39 (39%) (51%)		4 (4%) (13%)	56 (57%) (50%)
Highest frequency CCC categories² (source: administrative/claims files; n = 223)					
Cardiac	60 (27%)	21 (35%) (27%)	3 (5%) (60%)	12 (20%) (40%)	24 (40%) (22%)

Characteristics	Overall ¹ n = 223 # (Column %)	CoventryCares of Kentucky n = 77 # (Row %) (Column %)	Humana- CareSource n = 5 # (Row %) (Column %)	Passport Health Plan n = 30 # (Row %) (Column %)	WellCare of Kentucky n = 111 # (Row %) (Column %)
Brain/spinal cord anomaly	22 (10%)	7 (32%) (9%)		5 (23%) (17%)	10 (45%) (9%)
Infantile cerebral palsy	24 (11%)	6 (25%) (8%)		3 (13%) (10%)	15 (63%) (14%)
Congenital bone anomaly	19 (9%)	3 (16%) (4%)	1 (5%) (20%)	1 (5%) (3%)	14 (74%) (13%)
Hereditary immune deficiency	42 (19%)	17 (40%) (22%)	2 (5%) (40%)	9 (21%) (30%)	14 (33%) (13%)
Number of children with multiple CCC categories² (source: administrative/claims files; n = 223)					
0	84 (38%)	27 (32%) (35%)	2 (2%) (40%)	10 (12%) (33%)	45 (54%) (41%)
1	62 (28%)	25 (40%) (32%)	0	8 (13%) (27%)	29 (47%) (26%)
2+	77 (35%)	25 (32%) (32%)	3 (4%) (60%)	12 (16%) (40%)	37 (48%) (33%)
Highest frequency specific diagnoses³ (source: administrative/claims files; n = 223)					
Asthma	45 (20%)	11 (24%) (14%)	0	11 (24%) (37%)	23 (51%) (21%)
Diabetes	38 (17%)	12 (32%) (16%)	0	7 (18%) (23%)	19 (50%) (17%)
Failure to thrive	42 (19%)	18 (43%) (23%)	4 (10%) (80%)	5 (12%) (17%)	15 (36%) (14%)
Seizures/epilepsy	50 (22%)	17 (34%) (22%)	0	4 (8%) (13%)	29 (58%) (26%)
Esophageal reflux	51 (23%)	13 (25%) (17%)	2 (4%) (40%)	10 (20%) (33%)	26 (51%) (23%)

¹All children in foster care who were designated to have a mentally fragile status by the DCBS Medical Support Section and were enrolled in Medicaid managed care for the study period from July 1, 2013 to June 30, 2014.

²Complex chronic conditions (CCCs) are defined by ICD-9 codes in any setting during the study period (**Appendix A**).

³Highest frequency specific diagnoses are defined by ICD-9 codes in any setting during the study period (**Appendix B**).

Most of the children (76%; 80/105) were not dependent on technology for vital functions (**Table 2**). Level of technology dependence was defined using the following U.S. Congress, Office of Technology Assessment (OTA) definitions (OTA, 1987; Toly *et al.*, 2012): OTA group I: children dependent at least part of each day on mechanical ventilators; OTA group II: children requiring prolonged intravenous administration of nutritional substances or drugs (e.g., child has a “port-a-cath” for cancer treatment); OTA group III: children with daily dependence on other device-based respirator, or nutritional support, including tracheotomy tube care, suctioning, oxygen support, or tube feeding; and OTA group IV: children with prolonged dependence on other medical devices that compensate for vital body functions who require daily or near daily nursing care. This last group includes infants requiring apnea (cardio-respiratory) monitors, children requiring renal dialysis as a consequence of chronic kidney failure, and children requiring other medical devices such as urinary catheters or colostomy bags, as well as substantial nursing care in connection with their disabilities.

Table 2. Technology Dependence Prevalence and Level of Medically Fragile Children in Foster Care

Characteristics	Overall ¹ n = 105 # (Column %)	CoventryCares of Kentucky n = 32 # (Row %) (Column %)	Passport Health Plan n = 13 # (Row %) (Column %)	WellCare of Kentucky n = 60 # (Row %) (Column %)
Technology dependence prevalence and level (source: record review; n = 105)				
OTA group I	1 (1%)	0	0	1 (100%) (2%)
OTA group II	3 (3%)	2 (67%) (6%)	0	1 (33%) (2%)
OTA group III	19 (18%)	5 (26%) (16%)	3 (16%) (23%)	11 (58%) (18%)
OTA group IV	2 (2%)	1 (50%) (3%)	0	1 (50%) (2%)
No OTA group	80 (76%)	24 (30%) (75%)	10 (13%) (77%)	46 (58%) (77%)
Total (row %)	105 (100%)	32 (30%)	13 (12%)	60 (57%)

¹Total number of charts received for the medical record review sample were restricted to medically fragile children with at least six months of active designation as medically fragile during the study period (i.e., based upon medically fragile approval and release dates). Excluded were six children not enrolled in MCOs (two originally identified as CoventryCares of Kentucky members, one, as a Humana-CareSource member, and three, as WellCare of Kentucky members). As a result, there were no Humana-CareSource enrollees that fit the criteria for this analysis. OTA: U.S. Congress, Office of Technology Assessment. Column percentages for OTA groups were calculated using the last row as the denominator; this row represents the record review subsample.

Health Care Utilization for All Children Enrolled in MMC and for the Subset of Medically Fragile Children in Foster Care

Health care utilization rates were higher for medically fragile children in foster care, when compared with all MCO enrollees 0–20 years of age statewide (**Table 3**). The largest difference between these two groups was the number of hospital days per child; medically fragile children spent 16.67 days in the hospital on average, whereas all MCO enrollees combined spent 0.72 days in the hospital on average. Humana-CareSource and Passport Health Plan had the highest utilization rate among their medically fragile members (33.8 days per child and 31.3 days per child, respectively), while WellCare of Kentucky had the lowest rate (11.61 days per child). The number of home visits per child also varied substantially between these two groups; medically fragile children had an average of 7.65 visits per member, whereas all MCO enrollees had less than one visit on average (0.20). Passport Health Plan had the highest rate of home care utilization among medically fragile children (29.4 visits per child) whereas WellCare of Kentucky had the lowest rate (4.14 visits per child).

PCP utilization was about three times higher in the medically fragile sample compared with the overall MCO group (10.82 visits per child vs. 3.41 visits per child, respectively; **Table 3**). Similarly, medically fragile children visited the ED about three times as often as all MCO enrollees (3.12 visits per year vs. 0.95 visits per year, respectively). CoventryCares of Kentucky had the highest rate of ED utilization among medically fragile children (4.35 visits per year), whereas Passport Health Plan had the lowest rate (2.27 visits per year). Specialist visits per child varied somewhat (1.11 visits per child for medically fragile population vs. 0.30 visits per child for all MCO enrollees), as did hospitalizations (0.84 vs. 0.08, respectively). Dental visits were very similar between these two groups (0.88 visits per child for the medically fragile population vs. 0.81 for all MCO enrollees).

Table 3. Health Care Utilization for All Children Enrolled in MMC and for the Subset of Medically Fragile Children in Foster Care

Utilization	Overall	Anthem Blue Cross and Blue Shield Medicaid	CoventryCares of Kentucky	Humana-CareSource	Kentucky Spirit	Passport Health Plan	WellCare of Kentucky
All MCO enrollees 0–20 years of age							
Total enrollees	617,703	2,429	223,658	20,994	45	120,887	249,690
Hospitalizations	49,163	129	17,234	1,071	0	9,966	20,763
Hospitalization/child	0.08	0.05	0.08	0.05		0.08	0.08
Hospital days	445,442	806	115,939	8,731	0	159,109	160,857
Hospital days/child	0.72	0.33	0.52	0.42		1.32	0.64
ED visits	589,714	2,042	235,296	9,896	4	87,714	254,762
ED visits/child	0.95	0.84	1.05	0.47	0.09	0.73	1.02
Home visits	121,834	88	26,515	1,752	0	45,575	47,904
Home visits/child	0.20	0.04	0.12	0.08		0.38	0.19
PCP visits	2,108,554	3,221	849,231	25,862	4	233,331	996,905
PCP visits/child	3.41	1.33	3.80	1.23	0.09	1.93	3.99
Specialist visits	185,312	347	70,418	3,284	0	32,466	78,797
Specialist visits/child	0.30	0.14	0.31	0.16		0.27	0.32
Dental visits	503,043	650	195,857	5,682	2	111,806	189,046
Dental visits/child	0.81	0.27	0.88	0.27	0.04	0.92	0.76
Medically fragile children in foster care (Medicaid MCO enrollees 0–20 years of age) ¹							
Total enrollees	223		77	5		30	111
Hospitalizations	188		71	4		39	74
Hospitalization/child ²	0.84		0.92	0.80		1.30	0.67
% all MCO hospitalizations ³	0.38%		0.41%	0.37%		0.39%	0.36%
Hospital days	3,718		1,321	169		939	1,289
Hospital days/child ²	16.67		17.16	33.8		31.30	11.61
% all MCO hospital days	0.83%		1.14%	1.9%		0.59%	0.80%

Utilization	Overall	Anthem Blue Cross and Blue Shield Medicaid	CoventryCares of Kentucky	Humana-CareSource	Kentucky Spirit	Passport Health Plan	WellCare of Kentucky
ED visits	695		335	14		68	278
ED visits/child ²	3.12		4.35	2.8		2.27	2.50
% all MCO ED visits ³	0.12%		0.14%	0.14%		0.08%	0.11%
Home visits	1,705		324	39		882	460
Home visits/child ²	7.65		4.21	7.8		29.40	4.14
% all MCO visits ³	1.40%		1.22%	2.22%		1.94%	0.96%
PCP visits	2,412		870	34		175	1,333
PCP visits/child ²	10.82		11.30	6.8		5.83	12.01
% all MCO visits	0.11%		0.10%	0.13%		0.08%	0.13%
Specialist visits	248		92	1		17	138
Specialist visits/child ²	1.11		1.19	0.20		0.57	1.24
% all MCO visits ³	0.13%		0.13%	0.03%		0.05%	0.18%
Dental visits	196		76	0		25	95
Dental visits/child ²	0.88		0.99			0.83	0.86
% all MCO visits ³	0.04%		0.04%			0.02%	0.05%

¹Children were designated as medically fragile by the Kentucky DCBS Medical Support Section and enrolled in Medicaid managed care during the study period (July 1, 2013–June 30, 2014). There were no medically fragile children in foster care enrolled in Anthem Blue Cross and Blue Shield Medicaid or Kentucky Spirit health plans during the study period.

²Denominator = total enrollees for each column in table section, “Medically fragile children in foster care (Medicaid MCO enrollees 0–20 years of age).”

³Denominator = corresponding utilization count from table section, “All MCO enrollees 0–20 years of age.”

Health Care Utilization for All MMC Children not Designated as Medically Fragile and Subset of Foster Children, and Medically Fragile Children in Foster Care

The number of hospital days per medically fragile child in foster care was significantly greater than the number of hospital days for children in foster care who were not designated as medically fragile (16.67 days vs. 4.62 days; **Table 4**). Statistically significant differences were evident for ED visits per child (3.12 visits for medically fragile children in foster care vs. 0.93 visits for children in foster care who were not medically fragile), and PCP visits (10.82 visits for medically fragile children vs. 4.49 visits for children in foster care who were not medically fragile). The number of hospitalizations for each group in foster care was also significantly different (0.84 hospitalizations per medically fragile foster child vs. 0.14 hospitalizations for foster children who were not medically fragile).

Table 4. Health Care Utilization for All Children in MMC not Designated as Medically Fragile and Subset of Foster Care Children, and Medically Fragile Foster Care Children

Utilization	Medically Fragile Children in Foster Care ¹ (n = 223)	Children in Foster Care, Not Medically Fragile (n = 10,869)	Children in MMC, Not Medically Fragile (n = 617,480)
Hospitalizations			
Overall	188	1,478	48,975
Per child ^{2,3}	0.84	0.14	0.08
Standard deviation	1.24	0.49	0.32
Total hospital days			
Overall	3,718	50,254	441,724
Per child ^{2,3}	16.67	4.62	0.72
Standard deviation	45.68	30.72	9.32
ED visits			
Overall	695	10,108	589,019
Per child ^{2,3}	3.12	0.93	0.95
Standard deviation	5.05	2.29	2.29
PCP visits			
Overall	2,412	48,820	2,106,142
Per child ^{2,3}	10.82	4.49	3.41
Standard deviation	17.76	7.10	5.65

¹Children were designated as medically fragile by the Kentucky DCBS Medical Support Section and enrolled in Medicaid Managed Care (MMC) during the study period (July 1, 2013–June 30, 2014).

²Statistically significant differences were observed between means using *t* test with $P < 0.05$, comparing the means for medically fragile children to the means for children in foster care who were not medically fragile.

³Statistically significant differences were observed between means using *t* test with $P < 0.05$, comparing the means for medically fragile children to all children enrolled in MMC who were not medically fragile.

Possible Gaps in Identification of Medically Fragile Children in Foster Care

In order to identify possible gaps in the identification of medically fragile children in foster care, the analysis in **Table 5** further restricts the sample of members aged 0–20 years to children in foster care with at least one complex chronic condition (CCC), as well as hospital utilization patterns suggestive of “medically fragile,” or unstable, health status, i.e., two or more ED visits and two or more hospitalizations from June 30, 2013 through July 1, 2014. Among this vulnerable subpopulation, 30% (25/82) were designated as medically fragile, and 70% (57/82) were not. Children designated as medically fragile comprised 76% of children with three or more CCCs, whereas those not designated as medically fragile comprised 88% and 80% of children with one CCC and two CCCs, respectively. Children not designated as medically fragile comprised a substantially greater proportion of children with metabolic, lipid disorders (93%) and congenital bone anomalies (69%) compared to children designated as medically fragile (7% and 31%, respectively). On the other hand, children designated as medically fragile comprised a greater proportion (57%) of children with inherited immunodeficiencies. The distribution of children by medically fragile status among those with a cardiac CCC was similar.

Most of the children not receiving any specialty provider services were not designated as medically fragile (8/9 = 89%), yet children not designated as medically fragile also comprised most of the children with 3–6 different specialty provider types (9/15 = 60%; **Table 5**). Compared to children designated as medically fragile, children not designated as medically fragile were comprised of a smaller proportion with 8–26 ED visits (44% and 30%, respectively); however, children not designated as medically fragile comprised the majority of children within each ED visit frequency subgroup. Similarly, children not designated as medically fragile comprised 68%, 73% and 67% of children with 4–14, 15–47, and 55–298 hospital days, respectively.

Table 5. Possible Gaps in Identification of Medically Fragile Children in Foster Care

Clinical and Utilization Profile	Foster Care Children With Medically Fragile Designation ¹ (n = 25) # (Row %) (Column %)	Foster Care Children Not Designated as Medically Fragile (n = 57) # (Row %) (Column %)
CCCs		
1 CCC (n = 41)	5 (12%) (20%)	36 (88%) (63%)
2 CCCs (n = 20)	4 (20%) (16%)	16 (80%) (28%)
3-9 CCCs (n = 21)	16 (76%) (64%)	5 (24%) (9%)
Select types of CCCs²		
Immunodeficiency, hereditary (n = 30)	17 (57%) (68%)	13 (43%) (23%)
Cardiac (n = 27)	14 (52%) (56%)	13 (48%) (23%)
Metabolic, lipid (n = 27)	2 (7%) (8%)	25 (93%) (44%)
Congenital bone anomalies (n = 16)	5 (31%) (20%)	11 (69%) (19%)
Number of different specialty provider types³		
0 types (n = 9)	1 (11%) (4%)	8 (89%) (14%)
1 type (n = 33)	10 (30%) (40%)	23 (70%) (40%)
2 types (n = 25)	8 (32%) (32%)	17 (68%) (30%)
3-6 types (n = 15)	6 (40%) (24%)	9 (60%) (16%)
ED visits		
2-4 visits (n = 29)	8 (28%) (32%)	21 (72%) (37%)
5-7 visits (n = 25)	6 (24%) (24%)	19 (76%) (33%)
8-26 visits (n = 28)	11 (39%) (44%)	17 (61%) (30%)
Hospitalizations		
2 hospitalizations (n = 43)	11 (26%) (44%)	32 (74%) (56%)
3 hospitalizations (n = 21)	6 (29%) (24%)	15 (71%) (26%)
4-9 hospitalizations (n = 18)	8 (44%) (32%)	10 (56%) (18%)
Hospital days		
4-14 hospital days (n = 25)	8 (32%) (32%)	17 (68%) (30%)
15-47 hospital days (n = 30)	8 (27%) (32%)	22 (73%) (39%)
55-298 hospital days (n = 27)	9 (33%) (36%)	18 (67%) (32%)

¹Children were designated as medically fragile by the Kentucky DCBS Medical Support Section and enrolled in Medicaid Managed Care (MMC) during the study period (July 1, 2013-June 30, 2014).

²Complex chronic conditions (CCCs) are defined by ICD-9 codes in any setting during the measurement year (**Appendix A**).

³Specialty provider types represent specialty providers who saw the child in any setting during the study period (**Appendix C**).

Relational Coordination Survey of Care Coordination Team

Background and Response Rates

There were a total of 124 RC Survey participants out of a total of 212 who were invited to participate, for an overall survey response rate of 58%. Response rates by workgroups were as follows: MCO care/case managers: 69% (18/26); DCBS case managers: 53% (89/168); and CCSHCN foster care nurse consultant inspectors: 94% (17/18). Survey participants rated one another, as well as PCPs and specialist physicians, on the seven RC dimensions: frequent communication, timely communication, accurate communication, problem-solving communications, shared goals, shared knowledge, and mutual respect. The fully stated RC Survey questions that correspond to each of these dimensions can be found in **Appendix D**.

Overview

Summary findings indicate that timely communication and shared knowledge were potential limitations between workgroups; and therefore, opportunities for improvement, yet the dimensions of accurate communication and mutual respect also were weak (**Appendix D**). RC Survey findings also indicated that between workgroups, frequent communication, shared goals and problem-solving communication are overall strengths relative to the RC Index (a summary measure of the overall strength of RC across all dimensions; **Appendix D**), yet these dimensions were rated by the RC tool as moderate, rather than strong. Moreover, 90% of RC Surveys typically report frequent communication as strong; therefore, a finding of moderate strength merits additional consideration (Relational Coordination Analytics, personal communication, April 3, 2015).

Frequency of Communication by Workgroup

Drilling down by workgroup revealed that MCO care/case managers (**Figure 1**) and CCSHCN nurses (**Figure 2**) rated all other non-parent/guardian workgroups below the between workgroup mean (BWM; mean RC score based on responses given by participants about workgroups of which they are not a part) for frequency of communication. DCBS case managers rated MCOs, PCPs and specialty providers below the BMW for frequency of communication (**Figure 3**).

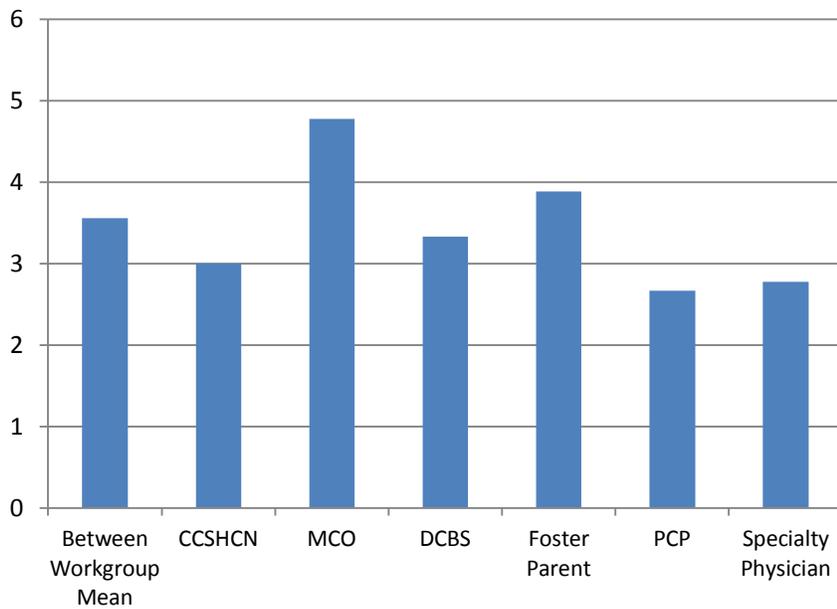


Figure 1. MCO Care/Case Managers Rate Workgroups on Frequent Communication. The mean rating of other care coordination team members by 18 MCO care/case managers for the RC Survey dimension of “frequent communication.” Rating scale: 1: not nearly enough; 2: much too often; 3: not enough; 4: too often; and 5: just the right amount.

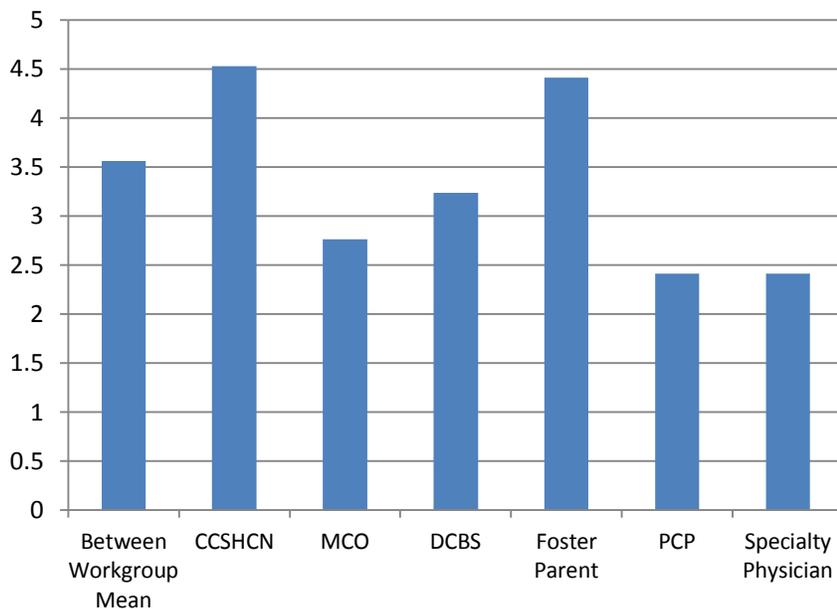


Figure 2. CCSHCN Nurses Rate Workgroups on Frequent Communication. The mean rating of other care coordination team members by 17 CCSHCN nurses for the RC Survey dimension of “frequent communication.” Rating scale: 1: not nearly enough; 2: much too often; 3: not enough; 4: too often; and 5: just the right amount.

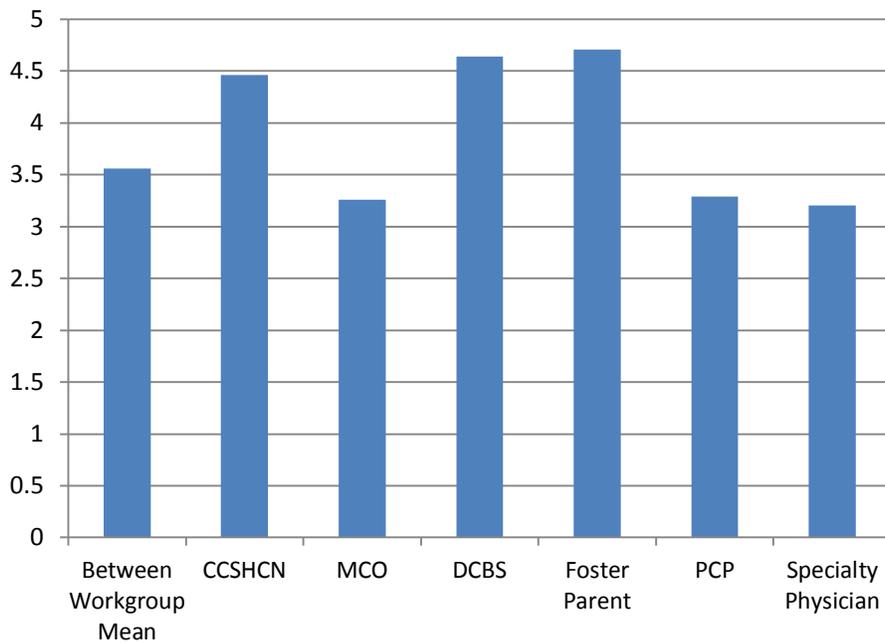


Figure 3. DCBS Case Managers Rate Workgroups on Frequent Communication. The mean rating of other care coordination team members by 89 DCBS case managers for the RC Survey dimension of “frequent communication.” Rating scale: 1: not nearly enough; 2: much too often; 3: not enough; 4: too often; and 5: just the right amount.

The RC Survey included two additional frequency-related questions asked uniquely of MCO care/case managers. In response to the question regarding frequency of CCSHCN foster care nurse consultant inspectors to provide the information needed about medically fragile children, 73% of MCO care/case managers answered “never,” “rarely” or “occasionally” (**Table 6**). Sixty-seven percent of MCO care/case managers responded “never,” “rarely” or “occasionally” regarding the frequency of specialist physicians providing the needed information, and 63%, regarding the frequency of PCPs providing the needed information. A smaller proportion of MCO care/case managers responded similarly regarding the frequency of the child’s guardian/foster parent providing needed information (35%); however, almost half of MCO care/case managers (47%) reported less than optimal access to the child’s foster parent/guardian (**Table 6**). Of note, 100% (3/3) of Anthem Blue Cross and Blue Shield Medicaid care/case managers surveyed responded “never,” “rarely” or “occasionally” to this question, the highest rate among MCOs. Interestingly, Anthem Blue Cross and Blue Shield Medicaid is the newest MCO to enroll members in Kentucky MMC.

Table 6. Custom Survey Questions Asked of MCOs, only: Access to Needed Information and Access to Child's Guardian/Foster Parent

MCO Custom Survey Questions	Overall (n = 18) ¹ #/n (% of n) ²	CoventryCares of Kentucky (n = 2) #/n (% of n) ²	Passport Health Plan (n = 7) #/n (% of n) ²	WellCare of Kentucky (n = 5) #/n (% of n) ²	Anthem Blue Cross and Blue Shield Medicaid (n = 3) #/n (% of n) ²	Humana-CareSource (n = 1) #/n (% of n) ²
1) How frequently do each of the workgroups listed below provide you with the information you need about medically fragile children who are in foster care and enrolled in Medicaid Managed Care? Answer: never, rarely, or occasionally						
MCO care/case managers (13 responses)	1/13 (8%)	0/2 (0%)	1/6 (17%)	0/2 (0%)	0/2 (0%)	0/1 (0%)
DCBS case managers (17 responses)	6/17 (35%)	1/2 (50%)	2/7 (29%)	2/5 (40%)	1/2 (50%)	0/1 (0%)
CCSHCN Foster Care Support nurse consultant inspectors (15 responses)	11/15 (73%)	1/2 (50%)	4/6 (67%)	3/4 (75%)	2/2 (100%)	1/1 (100%)
PCPs (16 responses)	10/16 (63%)	1/2 (50%)	5/7 (71%)	2/4 (50%)	1/2 (50%)	1/1 (100%)
Specialist physicians (15 responses)	10/15 (67%)	1/2 (50%)	5/7 (71%)	2/3 (67%)	1/2 (50%)	1/1 (100%)
Child's guardian/foster parent (17 responses)	6/17 (35%)	0/2 (0%)	2/7 (29%)	2/5 (40%)	1/2 (50%)	1/1 (100%)
2) How frequently are you able to obtain permission to contact the medically fragile child's foster parent/guardian ? Answer: never, rarely, or occasionally						
MCO care/case managers (17 responses)	8/17 (47%)	1/2 (50%)	2/7 (29%)	2/4 (50%)	3/3 (100%)	0/1 (0%)

¹Not all respondents answered every question; therefore, the overall total number of respondents exceeds the total number of respondents who answered any single question.

²The number and percentage of respondents who answered the question with "never," "rarely" or "occasionally" are shown.

Problem-Solving Communication

For the problem-solving communication dimension, the most notable result was that DCBS gave MCOs, PCPs and specialist physicians the lowest ratings, which can be attributed to relationships characterized by perceptions of “blaming” over problem solving (**Figure 4**).

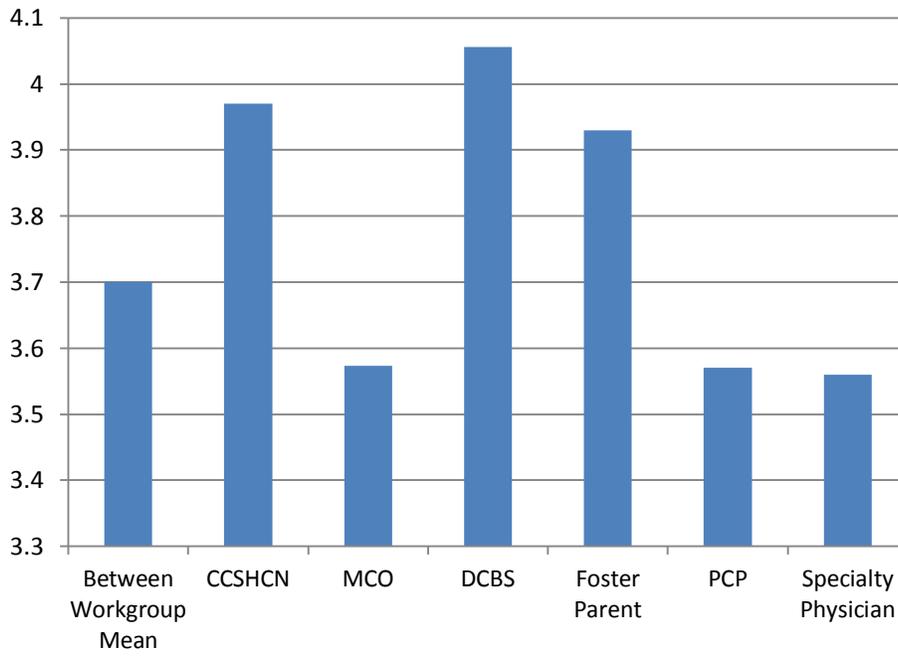


Figure 4. DCBS Case Managers Rate Workgroups on Problem-Solving Communication. The mean rating of other care coordination team members by 89 DCBS case managers for the RC Survey dimension of “problem-solving communication.” Rating scale: 1: always blame; 2: mostly blame; 3: neither blame nor solve; 4: mostly solve; and 5: always solve.

Mutual Respect

The low rating for between group mutual respect stands out because it is relationship-driven rather than communication process driven (Relational Coordination Analytics, personal communication, April 3, 2015), so raises questions about interactions other than communications about the members' care coordination. Both CCSHCN (Figure 5) and DCBS (Figure 6) rated MCOs, as well as PCPs and specialist physicians, lower than the BWM for mutual respect, whereas MCOs (Figure 7) rated CCSHCN, PCPs and specialist physicians, but not DCBS, as below the BWM for this same dimension. A pertinent consideration may be the finding that health plan authorization denial was the top barrier of extreme concern, tied with excessive caseload for frequency of extreme concern; however, the latter was of concern among a greater proportion of the DCBS and CCSHCN workgroup members than among the MCO workgroup members (Table 6). Health plan authorization delays ranked #3 for extreme concern overall (Table 7).

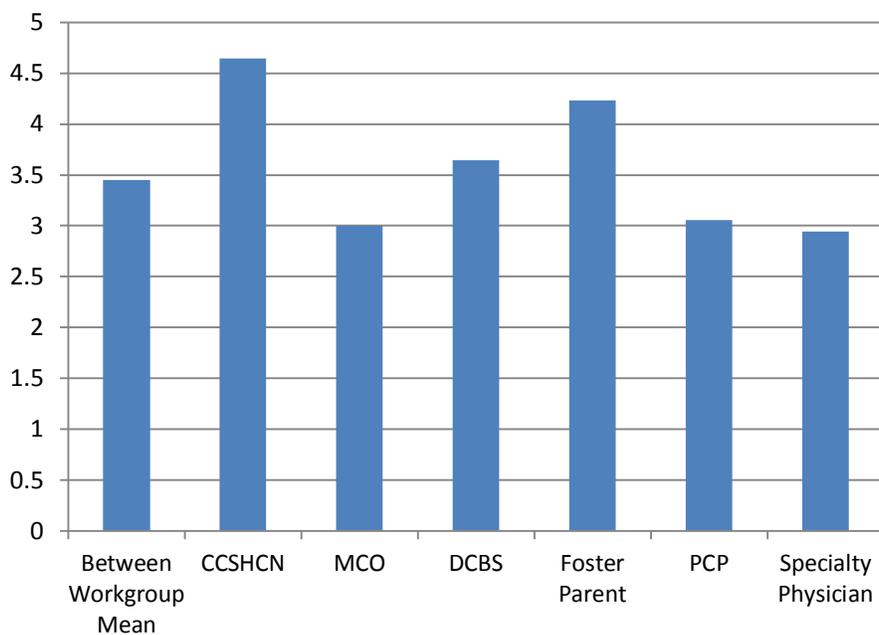


Figure 5. CCSHCN Nurses Rate Workgroups on Mutual Respect. The mean rating of other care coordination team members by 17 CCSHCN nurses for the RC Survey dimension of “mutual respect.” Rating scale: 1: not at all; 2: a little; 3: somewhat; 4: a lot; and 5: completely.

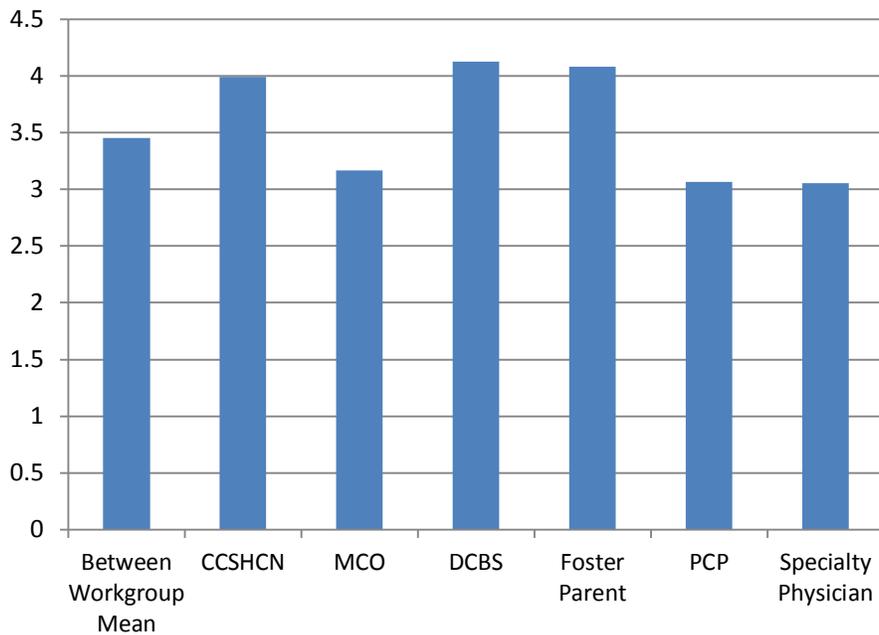


Figure 6. DCBS Case Managers Rate Workgroups on Mutual Respect. The mean rating of other care coordination team members by 89 DCBS case managers for the RC Survey dimension of “mutual respect.” Rating scale: 1: not at all; 2: a little; 3: somewhat; 4: a lot; and 5: completely.

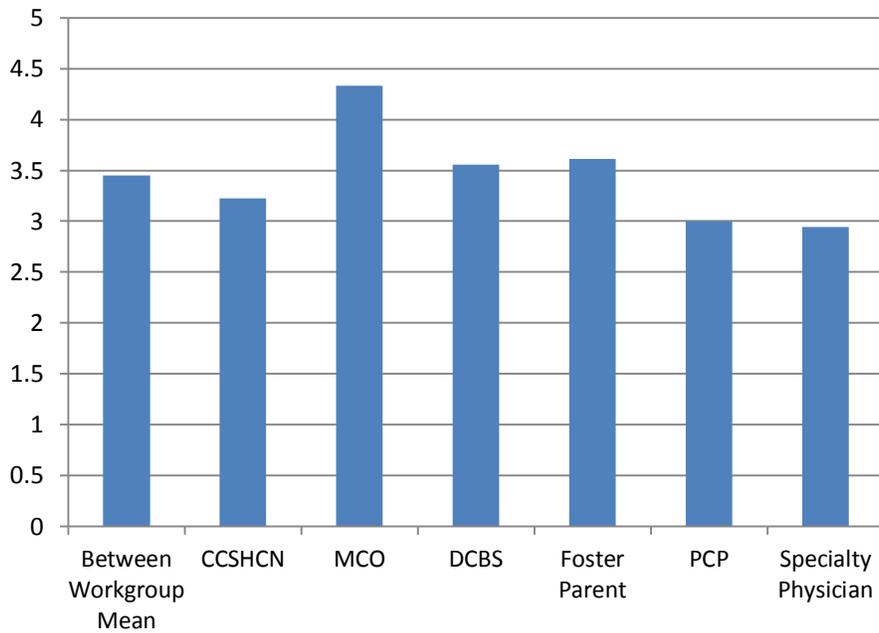


Figure 7. MCO Care/Case Managers Rate Workgroups on Mutual Respect. The mean rating of other care coordination team members by 18 MCO care/case managers for the RC Survey dimension of “mutual respect.” Rating scale: 1: not at all; 2: a little; 3: somewhat; 4: a lot; and 5: completely.

Highest Rated Groups

The highest rated groups overall were the CSHCN Foster Care Support nurse consultant inspectors and the child's guardian/foster parent (**Appendix D**); however, 28% of MCO care/case managers reported extreme concern regarding barriers to accessing the child's foster parent (**Table 7**).

Moreover, 47% of MCO care/case managers reported that they were "never," "rarely" or "occasionally" able to obtain permission to contact the medically fragile child's foster parent (**Table 6**).

Lowest Rated Groups

The lowest rated groups overall were specialist physicians and PCPs (**Appendix D**), with the lowest dimension ratings for shared knowledge (**Appendix D**). It is notable that the inability to find a provider within the area, inability to find a knowledgeable provider, and the inability to find a provider who accepts insurance ranked fourth, fifth and sixth as overall barriers of extreme concern, with 44%, 44%, and 28%, respectively, of MCO care/case managers expressing extreme concern; these MCO proportions represent statistically higher proportions relative to the other workgroups (**Table 7**). Other barriers with statistically significant differences in proportions among workgroups included access to the child's medical record, with the highest proportions of extreme concern reported by CSHCN (24%) and MCOs (22%); access to the foster parent, with the highest proportion of extreme concern reported by MCOs (28%); correct identification of the child's health plan membership, with the highest proportion of extreme concern reported by MCOs (24%); literacy barriers, with the highest proportion of extreme concern reported by CSHCN (18%) and MCOs (17%); and language barriers, with the highest proportion of extreme concern reported by MCOs (17%; **Table 7**).

Table 7 Custom Survey Question Asked of CCSHCN, DCBS and MCO Participants: Barriers to Providing Care

Barrier ¹	Total Across All Workgroups (n = 124) {Overall Rank} ²	CCSHCN Foster Care Support Nurse Consultant Inspectors (n = 17)	DCBS Case Managers (n = 89)	MCO Care/Case Managers (n = 18)
Health plan denies authorization for needed care/services	44/123 (36%) {1}	8/17 (47%)	32/88 (36%)	4/18 (22%)
Excessive caseload ³	44/124 (35%) {2}	4/17 (24%)	39/89 (44%)	1/18 (6%)
Health plan delays authorization for needed care/services	38/124 (31%) {3}	7/17 (41%)	28/89 (31%)	3/18 (17%)
Unable to find needed services/provider in area (e.g., transportation problems)	35/123 (28%) {4}	6/17 (35%)	21/88 (24%)	8/18 (44%)
Unable to find provider who knows how to treat child's specific condition(s)	33/123 (27%) {5}	3/17 (18%)	22/88 (25%)	8/18 (44%)
Unable to find provider who accepts insurance ³	25/124 (20%) {6}	3/17 (18%)	17/89 (19%)	5/18 (28%)
Confidentiality regulations/access to child's medical record ³	14/124 (11%) {7}	4/17 (24%)	6/89 (7%)	4/18 (22%)
Confidentiality regulations/access to child's guardian/foster parent ³	11/123 (9%) {8}	2/16 (13%)	4/89 (4%)	5/18 (28%)
Correct identification of child's health plan membership ³	11/122 (9%) {8}	2/17 (12%)	5/88 (6%)	4/17 (24%)
Literacy barriers, child's guardian/foster parent ³	10/124 (8%) {9}	3/17 (18%)	4/89 (4%)	3/18 (17%)
Language barriers, child's guardian/foster parent ³	9/124 (7%) {10}	1/17 (6%)	5/89 (6%)	3/18 (17%)

¹Number and percentage of respondents who answered the question "How concerned are you about each of the following barriers to providing the type of care you want to provide?" with "extremely concerned" are shown. Percentages were calculated using the number of respondents for each question as the denominator, which differed slightly from the overall denominators, as not every respondent answered every question

²Rank order of overall percentages, from highest {1} to lowest {10}, with the same ranking indicating a tie percentage ranking.

³Statistically significant difference in proportions among workgroups using *chi*-square statistic $P < 0.05$ or, for responses with low workgroup response counts, Fisher's exact test $P < 0.05$.

Inter-Workgroup Rating on RC Dimensions of Communications

Table 8 presents survey participant workgroups (non-survey participant PCPs and specialist physicians are excluded) who were rated by the other survey participant workgroups as below the BWM for the dimensions pertinent to communication processes. MCO care/case managers received the lowest ratings from CCSHCN and DCBS across all dimensions pertinent to communication processes. CCSHCN nurse consultant inspectors received the lowest ratings from MCOs for frequent, timely and accurate communication, with DCBS case managers also rated by MCOs as below the mean for these same dimensions.

Table 8. Inter-Workgroup Rating on RC Dimensions of Communication

Rater ¹	RC Dimension: Communication			
	Frequent Communication	Timely Communication	Accurate Communication	Problem-Solving Communication
CCSHCN	MCO < DCBS	MCO	MCO < DCBS	MCO < DCBS
DCBS	MCO	MCO	MCO	MCO
MCO	CCSHCN < DCBS	CCSHCN < DCBS	CCSHCN < DCBS	None below mean

¹Workgroups that received ratings by CCSHCN, DCBS, and MCO members that were below the between workgroup mean (BWM) for the dimensions of communication processes in the Relational Coordination (RC) Survey are shown. The first workgroup preceding the < symbol had a lower rating than the workgroup following the < symbol.

Inter-Workgroup Rating on RC Dimensions of Coordination Relationships

Table 9 presents survey participant workgroups (non-survey participant PCPs and specialist physicians are excluded) who were rated by other survey participant workgroups as below the BWM for the dimensions pertinent to coordination relationships. MCO care/case managers received the lowest ratings from CCSHCN and DCBS across all dimensions pertinent to coordination relationships. CCSHCN nurse consultant inspectors received the lowest ratings from MCOs for shared goals, shared knowledge and mutual respect. DCBS case managers were also rated by MCOs as below the mean for the dimension of shared knowledge.

Table 9. Inter-Workgroup Rating on RC Dimensions of Coordination Relationships

Rater ¹	RC Dimension: Coordination Relationships		
	Shared Goals	Shared Knowledge	Mutual Respect
CCSHCN	MCO	MCO	MCO
DCBS	MCO	MCO	MCO
MCO	CCSHCN	CCSHCN < DCBS	CCSHCN

¹Workgroups that received ratings by CCSHCN, DCBS, and MCO members that were below the between workgroup mean (BWM) for the dimensions of coordination relationships in the Relational Coordination (RC) Survey are shown. The first workgroup preceding the < symbol had a lower rating than the workgroup following the < symbol.

Care/Case Management Record Review of Medically Fragile Children

Background

MCO, DCBS and CCSHCN care/case management records were requested for a total of 111 MMC enrollees with at least six months of actively designated medically fragile status during the period from July 1, 2013 to June 30, 2014. Of those 111 children, 6 were excluded from the record review due to MCO documentation that the child was not enrolled in the MCO, for a resultant total of 105 children in the record review sample.

Outreach

MCO care/case managers outreached to DCBS at least once for 67% (70/105) of medically fragile children, but to CCSHCN for only 15% (16/105) of medically fragile children (**Table 10**). MCO care/case managers were notified of medically fragile designation for 63% (66/105) of children, including 45% (30/66) with DCBS and 2% (1/66) with CCSHCN as the notification source (**Table 11**). Chart review findings indicate that there was no documented MCO outreach to PCPs and specialist physicians for the vast majority, i.e., 80% (84/105) and 85% (89/105), respectively, of medically fragile children (**Table 10**). MCO chart findings also indicate that half (52/105) of the foster parents were never outreached at least once by MCO care/case managers, 56% (59/105) of parents were never contacted, and only 11% (12/105) of MCO charts contained care plans that documented collaboration with the foster parent (**Table 11**).

Table 10. Care/Case Management Record Review: MCO Outreach

MCO Outreach ¹	Overall 105 (100%)	CoventryCares of Kentucky 32 (30%)	Passport Health Plan 13 (12%)	WellCare of Kentucky 60 (57%)
MCO outreach to foster parents/guardians				
None	52 (50%)	10 (31%)	2 (15%)	40 (67%)
Once	4 (4%)	1 (3%)	0	3 (5%)
Twice	9 (9%)	4 (13%)	0	5 (8%)
Three or more times	40 (38%)	17 (53%)	11 (85%)	12 (20%)
Foster parent/guardian contacted	46 (44%)	20 (63%)	9 (69%)	17 (28%)
Foster parent/guardian engaged in MCO CM	16 (15%)	4 (13%)	8 (62%)	4 (7%)
MCO outreach to PCPs				
None	84 (80%)	25 (78%)	8 (62%)	51 (85%)
Once	10 (10%)	1 (3%)	5 (38%)	4 (7%)
Twice	5 (5%)	2 (6%)	0	3 (5%)
Three or more times	6 (6%)	4 (13%)	0	2 (3%)
PCP contacted	14 (13%)	5 (16%)	1 (8%)	8 (13%)
MCO outreach to specialist physicians				
None	89 (85%)	26 (81%)	7 (54%)	56 (93%)
Once	3 (3%)	2 (6%)	1 (8%)	0
Twice	1 (1%)	0	1 (8%)	0
Three or more times	12 (11%)	4 (13%)	4 (31%)	4 (7%)
Specialist physician contacted	13 (12%)	5 (16%)	4 (31%)	4 (7%)
MCO outreach to DCBS				
None	35 (33%)	5 (16%)	2 (15%)	28 (47%)
Once	20 (19%)	5 (16%)	4 (31%)	11 (18%)
Twice	10 (10%)	5 (16%)	2 (15%)	3 (5%)
Three or more times	40 (38%)	17 (53%)	5 (38%)	18 (30%)
MCO outreach to CSHCN				
None	89 (85%)	27 (84%)	11 (85%)	51 (85%)
Once	7 (7%)	2 (6%)	1 (8%)	4 (7%)
Twice	2 (2%)	1 (3%)	0	1 (2%)
Three or more times	7 (7%)	2 (6%)	1 (8%)	4 (7%)

¹Case management record review findings for medically fragile children in foster care enrolled in MMC (n = 105), with at least six months medically fragile status for the measurement year from July 1, 2013 to June 30, 2014.

Table 11. Care/Case Management Record Review: MCO Needs Assessment and Care Planning

MCO Needs Assessment and Care Planning ¹	Overall 105 (100%)	CoventryCares of Kentucky 32 (30%)	Passport Health Plan 13 (12%)	WellCare of Kentucky 60 (57%)
MCO Comprehensive Needs Assessment (CNA)				
None	53 (50%)	20 (63%)	2 (15%)	31 (52%)
Prior to MY, only	7 (7%)	0	2 (15%)	5 (8%)
During MY	45 (43%)	12 (38%)	9 (69%)	24 (40%)
MCO plan of care (POC)	19 (18%)	2 (6%)	11 (85%)	6 (10%)
MCO POC developed in collaboration with:				
Foster parent/guardian	12 (11%)	1 (3%)	8 (62%)	3 (5%)
DCBS	0	0	0	0
CCSHCN	0	0	0	0
PCP	2 (2%)	0	1 (8%)	1 (2%)
Specialist physician	0	0	0	0
MCO POC updates	14 (13%)	3 (9%)	7 (54%)	4 (7%)
Other POC				
DCBS Service Plan (SP)	7 (7%)	0	2 (15%)	5 (8%)
SP signed by MCO and DCBS	2 (2%)	0	2 (15%) note: no CM referral, "not needed"	0
DCBS Individual Health Plan	9 (9%) note: not signed by MCO	0	0	9 (15%)
Other communication with DCBS/CCSHCN for POC	33 (31% with DCBS or CCSHCN) (76% with DCBS)	10 (31%)	5 (38%)	18 (30%)
MCO met with DCBS at least once	14 (13%)	0	5 (38%)	9 (15%)
MCO Care Coordination (CC)	47 (45%)	17 (53%)	11 (85%)	19 (32%)
Physical CC	44/47 (94%)	17/17 (100%)	10/11 (91%)	17/19 (89%)
Behavioral CC	27/47 (57%)	10/17 (59%)	6/11 (55%)	11/19 (58%)
Functional CC	34/47 (72%)	13/17 (76%)	8/11 (73%)	13/19 (68%)
Durable Medical Equipment CC	30/47 (64%)	12/17 (71%)	6/11 (55%)	12/19 (63%)
Social CC	34/47 (72%)	12/17 (71%)	9/11 (82%)	13/19 (68%)
MCO notified of medically fragile designation ²	66 (63%)	22 (69%)	11 (85%)	33 (55%)
By DCBS	30/66 (45%)	7/22 (32%)	8/11 (73%)	15/33 (45%)
By CCSHCN	1/66 (2%)	0	0	1/33 (3%)
By foster parent/guardian	3/66 (5%)	0	1/11 (9%)	2/33 (6%)

¹Care/Case management record review findings for medically fragile children in foster care enrolled in MMC (n = 105), with at least six months medically fragile status for the measurement year (MY) from July 1, 2013 to June 30, 2014.

²Unable to determine definitive medically fragile notification source other than case management notes. Also, source was noted for five members on the Kentucky Medically Fragile list.

Care Plans

Only 18% (19/105) of MCO charts for medically fragile children included documentation of an MCO care plan; these care plans showed minimal (12/105; 11%) collaboration with the foster parent and at most minimal collaboration with DCBS, CCSHCN, PCPs and specialist physicians (**Table 11**). None of the DCBS and CCSHCN charts contained MCO care plans (**Table 12**). On the other hand, 86% (90/105) of DCBS charts reviewed contained the DCBS Individual Health Care Plan (IHCP), as did 88% (92/105) of CCSHCN charts, but only 9% (9/105) of MCO charts (**Table 12**). DCBS and CCSHCN charts showed regional variability of IHCP documentation; 86% of DCBS charts included the IHCP, with a range of 60–100% across regions (**Table 13**), and 88% of CCSHCN charts included the IHCP, with a range of 67–100% across regions (**Table 14**.)

Comprehensive Needs Assessment

MCO comprehensive needs assessments were conducted for half of the medically fragile children (**Table 11**). In order to collaboratively determine each child’s medical needs and identify the need for placement in case management, Kentucky Medicaid contract language requires, for each child in foster care, preparation of a service plan by DCBS that is forwarded to the MCO, with DCBS and MCO signatures indicating agreement with the plan. Yet, only 2% (2/105) of MCO and DCBS charts, and none of the CCSHCN charts, included evidence of initial RC via a collaborative service plan (with MCO and DCBS or CCSHCN signatures) consistent with the contract language (**Table 12**).

Care Coordination

MCO care coordination activity showed variability across MCOs, ranging from 32% (19/60; WellCare of Kentucky) to 53% (17/32; CoventryCares of Kentucky) to 85% (11/13; Passport Health Plan; **Table 11**). None of the MCO care/case management charts included the “Child/Youth Information Sheet” or “Family Case Plan” used to document a current or reviewed Medical Passport, the child’s health care record maintained by the foster parent, compared to 48% and 50% of DCBS and CCSHCN records, respectively (**Table 12**). CCSHCN home visit encounter summaries for more than half of each child’s duration of medically fragile status were found in 67% (70/105) of CCSHCN charts, 50% (53/105) of DCBS charts, but in none of the MCO charts (**Table 12**). DCBS and CCSHCN charts showed regional variability in documentation of encounter home visit summaries for more than half of each child’s duration of medically fragile status; ranging from 0–78% across regions for DCBS charts (**Table 13**), and ranging from 50–79% across regions for CCSHCN charts (**Table 14**). There was no clear identification of a lead care coordinator, as agreed upon by MCO, DCBS and CCSHCN staff.

Table 12. Cross-Agency Documentation of Care/Case Management

Documentation of Care/Case Management ¹	MCOs, Overall (n=105)	CoventryCares of Kentucky	Passport Health Plan	WellCare of Kentucky	DCBS	CCSHCN
MCO care plan	19 (18%)	2 (2%)	11 (10%)	6 (6%)	0	0
DCBS Service Plan with MCO and DCBS or CCSHCN signatures	2 (2%)	0	2 (2%)	0	2 (2%)	0
DCBS Individual Health Care Plan	9 (9%)	0	0	9 (9%)	90 (86%)	92 (88%)
DCBS Individual Health Care Plan with foster parent signature	6 (6%)	0	0	6 (6%)	63 (60%)	1 (1%)
Medical Passport current or reviewed per Child/Youth Information Sheet or Family Case Plan	0	0	0	0	50 (48%)	53 (50%)
CCSHCN Medically Fragile Home Visit Encounter Summaries for more than half of the months with medically fragile status	0	0	0	0	53 (50%)	70 (67%)

¹Care/Case management record review findings for medically fragile children in foster care enrolled in MMC (n = 105), with at least six months medically fragile status for the measurement year (MY) from July 1, 2013 to June 30, 2014.

Table 13. Care/Case Management Record Review: DCBS Case Management

DCBS Region ¹	DCBS Service Plans with MCO + DCBS/CCSHCN Signatures # (Row %)	DCBS Individual Health Care Plan # (Row %)	DCBS Individual Health Care Plan with Foster Parent Signature # (Row %)	DCBS Request for Approval as Medically Fragile Form # (Row %)	Medical Passport Current or Reviewed per Child/Youth Information Sheet or Family Case Plan # (Row %)	CCSHCN Medically Fragile Home Visit Encounter Summaries for more than half of the Months with Medically Fragile Status # (Row %)
All regions (n = 105; 100%)	2 (2%)	90 (86%)	63 (60%)	33 (31%)	50 (48%)	53 (50%)
Two Rivers (n = 25; 24%)	0	23 (92%)	19 (76%)	7 (28%)	15 (60%)	16 (64%)
Salt River Trail (n = 4; 4%)	0	4 (100%)	2 (50%)	2 (50%)	4 (100%)	3 (75%)
Jefferson (n = 8; 8%)	0	5 (63%)	3 (38%)	4 (50%)	5 (63%)	0
Northern Bluegrass (n = 18; 18%)	0	18 (100%)	8 (44%)	0	0	14 (78%)
Northeastern (n = 6; 6%)	1 (17%)	5 (83%)	4 (67%)	4 (67%)	3 (50%)	4 (67%)
Eastern Mountain (n = 8; 8%)	0	7 (88%)	5 (63%)	5 (63%)	0	1 (13%)
Cumberland (n = 10; 10%)	1 (10%)	6 (60%)	4 (40%)	4 (40%)	6 (60%)	5 (50%)
Southern Bluegrass (n = 14; 13%)	0	13 (93%)	12 (86%)	2 (14%)	9 (64%)	6 (43%)
The Lakes (n = 12; 11%)	0	9 (75%)	6 (50%)	5 (42%)	8 (67%)	4 (33%)

¹Care/Case management record review findings for medically fragile children in foster care enrolled in MMC (n = 105), with at least six months medically fragile status for the measurement year (MY) from July 1, 2013 to June 30, 2014.

Table 14. Care/Case Management Record Review: CCSHCN Case Management

DCBS Region ¹	DCBS Service Plans with MCO + DCBS/CCSHCN Signatures # (Row %)	DCBS Individual Health Care Plan # (Row %)	DCBS Individual Health Care Plan with Foster Parent Signature # (Row %)	DCBS Request for Approval as Medically Fragile Form # (Row %)	Medical Passport Current or Reviewed per Child/Youth Information Sheet or Family Case Plan # (Row %)	CCSHCN Medically Fragile Home Visit Encounter Summaries for more than half of the Months with Medically Fragile Status # (Row %)
All regions (n = 105; 100%)	0	92 (88%)	1 (1%)	0	1 (1%)	70 (67%)
Two Rivers (n = 25; 24%)	0	23 (92%)	1 (4%)	0	1 (4%)	19 (76%)
Salt River Trail (n = 4; 4%)	0	4 (100%)	0	0	0	3 (75%)
Jefferson (n = 8; 8%)	0	6 (75%)	0	0	0	4 (50%)
Northern Bluegrass (n = 18; 18%)	0	16 (89%)	0	0	0	14 (78%)
Northeastern (n = 6; 6%)	0	4 (67%)	0	0	0	3 (50%)
Eastern Mountain (n = 8; 8%)	0	7 (88%)	0	0	0	4 (50%)
Cumberland (n = 10; 10%)	0	9 (90%)	0	0	0	5 (50%)
Southern Bluegrass (n = 14; 13%)	0	13 (93%)	0	0	0	11 (79%)
The Lakes (n = 12; 11%)	0	10 (83%)	0	0	0	7 (58%)

¹Care/Case management record review findings for medically fragile children in foster care enrolled in MMC (n = 105), with at least six months medically fragile status for the measurement year (MY) from July 1, 2013 to June 30, 2014.

Care/Case Management Service Authorization Denials Review of Medically Fragile Children

Among the record review sample, there were 21 (21/105 = 20%) children for whom the MCOs provided utilization management records that documented service denials; of these denials, none were appealed. A summary of denial findings by case/service type and MCO is presented in **Table 15**. Adolescents with co-occurring diabetes and behavioral health problems, and whose continued psychiatric residential treatment facility (PRTF) stays were restricted, comprised the largest denial case/service type (7/21; 33%); this was the highest volume case/service denial type for WellCare of Kentucky, as well (4/10; 40%; **Table 15**). Specific findings for care/case management for this case/service denial type were described using a narrative format; thus, data is not shown in tables. Typical clinical scenarios entailed self-harm behaviors enabled by the member's diabetic condition, e.g., non-compliance with insulin use and/or dietary restrictions, and consequent inpatient hospitalization for diabetes and/or psychiatric hospitalization. Of note, among the entire chart review sample, diabetic ketoacidosis was the highest volume hospital principal diagnosis, and hospitalizations were also attributable to behavioral diagnoses that included depression, bipolar disorder and episodic mood disorders (**Appendix E**).

Each MCO had at least one diabetic member with a denial of continued PRTF stay. Of note, 100% (7/7) of these members' foster parents were outreached by the MCOs (data not shown), compared to 50% of the overall sample (**Table 10**). Moreover, 71% (5/7) of these members' foster parents were successfully engaged in MCO care management services, compared to 15% of the overall sample (**Table 10**), and the MCO record contained documentation that a comprehensive needs assessment was conducted for each of these seven adolescents (7/7; 100%) during the measurement year, compared to 43% (45/105) of the overall sample (**Table 11**). Both physical and behavioral health needs were assessed for each of these adolescents; social needs of six of the seven adolescents were also assessed. In addition, 100% (7/7) of these adolescents' MCO care management records showed evidence of care coordination, compared to 45% (47/105) of the overall record review sample (**Table 11**).

Yet, for the subset of adolescents with service denials for continued PRTF stays, only 43% (3/7) and 57% (4/7) of PCPs and specialist physicians, respectively, were contacted during the measurement year (data not shown). Although 71% (5/7) of this subset's MCO records contained an MCO care plan,

and four of the five were developed in collaboration with the foster parent, there was no evidence of care plan collaboration with DCBS, CCSHCN staff or specialist physicians, and only one MCO care plan had evidence of PCP collaboration (data not shown). Only three of the seven (43%) adolescents' charts documented ongoing updates to the care plan. Although MCO care/case managers met with DCBS staff for most (5/7; 71%; data not shown) of the adolescents in this subset, compared to only 13% of the overall record review sample (**Table 11**), none of the MCO charts for this subset contained a collaborative service plan or documentation of a current or reviewed Medical Passport, and only one contained the DCBS IHCP.

Children with development delays comprised 24% (5/21) of denial case/service types (**Table 15**); this was the highest volume case/service denial type for CoventryCares of Kentucky (4/8; 50%), primarily attributable to limitations on the number of speech, occupational, and physical therapies (3/4; 75%). Children with sleep apnea comprised 14% (3/21) of denial case/service types (**Table 15**). One Passport Health Plan member was denied authorization for respiratory syncytial virus (RSV) prophylaxis, despite documentation of receipt of respiratory therapy. Of the three members with a diagnosis of cleft lip or palate, only one was denied a service authorization during the study period, i.e., aforementioned RSV prophylaxis denial, and this member was too young for repair of cleft lip/palate. The other two members had already undergone cleft lip/palate repair (data not shown).

Table 15. Review of Service Authorization Denials

Denial Case/Service Type	Total n = 21	CoventryCares of Kentucky n = 8	Passport Health Plan n = 3	WellCare of Kentucky n = 10
Diabetes <u>with</u> co-occurring behavioral health problems: denial of continued stay in psychiatric residential treatment facility due to less intensive level of care (LOC) indicated	7	1	2	4
Mood/depressive disorder <u>without</u> co-occurring diabetes	2	1 denial of non-formulary medication	0	1 denial of Impact Plus due to LOC
Diabetes <u>without</u> co-occurring behavioral health problems: denial of inpatient admission for hyperglycemia in type-1 diabetes mellitus due to "absence of extenuating circumstances"	1	1	0	0
Spina bifida: denial of irrigation supplies beyond maximum allowable per month	1	0	0	1
Spina bifida: denial of magnetic resonance	1	0	0	1

Denial Case/Service Type	Total n = 21	CoventryCares of Kentucky n = 8	Passport Health Plan n = 3	WellCare of Kentucky n = 10
imaging (MRI) due to inappropriate MRI type coded				
Other MRI denial due to inappropriate MRI type coded: chest/arm to rule out thrombosis	1	0	0	1
Sleep apnea	3	2 denial of 1) non-FDA approved medication and 2) pulse oximeter to first member; denial of continuous positive airway pressure (CPAP) beyond one month to second member. ¹	0	1 denial of sleep lab monitoring
Developmental delay: denial of therapies (speech therapy [ST], occupational therapy [OT], physical therapy [PT], skilled nursing [SN])	3 (includes one member also counted for sleep apnea case type ¹)	3 denial of ST beyond 12 visits ¹ to first member; denial of SN and OT beyond 12 visits to second member; denial of PT/OT/ST in-home due to lack of medical necessity to third member	0	0
Developmental delay: denial of poly-vi-sol	1	1	0	0
Developmental delay: denial of iPad due to non-coverage by Kentucky Medicaid	1	0	0	1
Congenital heart anomaly: denial of Synagis for RSV prophylaxis due to lack of documentation of 1) hemodynamically significant issues and 2) respiratory therapy	1	0	1 (Provider did document member receipt of albuterol nebulizer)	0

¹Same member with two denials, in separate case/service type categories. Some members have more than one denial for the same case/service type; denial counts are not indicated.

Discussion

Medically fragile children enrolled in Kentucky MMC plans utilize a disproportionate amount of hospital inpatient and ED services. This susceptible subset of children in foster care comprise only 0.04% (223/617,703) of the MMC enrollee population 0–20 years of age, but represent 0.83% (3,718/445,442) and 0.12% (695/589,714) of inpatient hospital days and ED visits, respectively. Compared to children in foster care who were not designated as medically fragile, the number of hospital days per medically fragile child was significantly greater (17 days vs. 5 days). Coordination of care for medically complex and fragile children has been shown to reduce the number of hospital days (Gordon *et al.*, 2007), and the pattern of interaction among the care coordination team was shown to be the most influential factor on the quality of care coordination (McEvoy *et al.*, 2011). Therefore, gaps in care coordination represent opportunities to enhance the quality of care provided for medically fragile children, as well as to potentially reduce the costs of care. Key barriers to coordination of care for medically fragile children enrolled in Kentucky MMC include lack of care coordination with PCPs and specialist physicians, lack of MCO care/case manager access to the foster parent, and lack of MCO engagement as part of the medically fragile care coordination team.

Lack of RC with PCPs and specialist physicians is a reported barrier to care coordination for medically fragile children. RC Survey findings revealed that, of all the workgroups evaluated (MCO care/case managers, DCBS social workers/case managers, CSHCN Foster Care Support nurse consultant inspectors, foster parents/guardians, PCPs, and specialist physicians), PCPs and specialist physicians received the lowest overall RC ratings. PCPs and specialist physicians were rated below the workgroup mean by all three survey participant workgroups (MCO, DCBS, and CSHCN, across all dimensions, i.e., frequent communication, timely communication, accurate communication, problem-solving communication, shared goals, shared knowledge, and mutual respect). Furthermore, 67% and 63% of MCO care/case managers reported that specialist physicians and PCPs, respectively, “never,” “rarely” or “occasionally” provide needed information on medically fragile children. Yet, chart review findings indicate that there was no documented MCO outreach to PCPs and specialist physicians for the vast majority (80% and 85%, respectively) of medically fragile children.

Survey findings suggest the existence of barriers to access and availability of PCPs and specialist physicians. Specifically, extreme concern regarding inability to find needed services and/or a provider in the area was reported by 28% of respondents and extreme concern regarding inability to find a

provider who knows how to treat children's specific conditions was reported by 27% of respondents, with 44% of MCO respondents indicating extreme concern regarding each of these barriers.

Lack of MCO care/case manager access to the foster parent is a barrier to MCO provision of care coordination for medically fragile children. Almost half (47%) of MCO care/case manager survey respondents indicated that they "never," "rarely" or "occasionally" are able to obtain permission to contact the medically fragile child's foster parent. MCO chart findings are consistent with this finding. Specifically, half of the foster parents were never outreached by MCO care/case managers, 56% of parents were never contacted, and only 11% of MCO charts contained care plans that documented collaboration with the foster parent. Foster parents received RC ratings at or above the BWM with one exception: MCO care/case managers rated foster parents below the mean on the dimension of shared knowledge. Chart review findings showed that none of the MCO care/case management charts included the "Child/Youth Information Sheet," which is used to document a current Medical Passport, the child's health care record maintained by the foster parent.

There is a lack of MCO engagement as part of the medically fragile child care coordination team. Among the care coordination team survey participants (MCOs, DCBS, CCSHCN), the MCO workgroup received the lowest ratings from CCSHCN and DCBS workgroups across all communication survey dimensions (frequent, timely, accurate and problem-solving communication) and across all coordination relationship dimensions (shared goals, shared knowledge and mutual respect). Across all survey dimensions, CCSHCN was rated lower than DCBS by the MCO workgroup. Moreover, 73% of the MCO workgroup indicated that the CCSHCN nurse consultant "never," "rarely" or "occasionally" provided the information needed about medically fragile children.

Chart review findings indicate that MCO care/case managers were notified of medically fragile designation for 63% of children, including 45% with DCBS and 2% with CCSHCN as the notification source. Chart review findings also showed that MCO care/case managers outreached to DCBS for 67% of medically fragile children, but to CCSHCN for only 15% of medically fragile children. Yet, only 18% of MCO charts for medically fragile children included documentation of an MCO care plan; these care plans showed at most minimal collaboration with DCBS, CCSHCN, PCPs and specialist physicians. None of the DCBS and CCSHCN charts contained MCO care plans.

MCO CNAs were conducted for half of the medically fragile children, and MCO care coordination activity showed variability across MCOs, ranging from 32% (WellCare of Kentucky) to 53%

(CoventryCares of Kentucky) to 85% (Passport Health Plan). On the other hand, 86% of DCBS charts reviewed contained the DCBS IHCP, as did 88% of CSHCN charts, but only 9% of MCO charts contained an IHCP. CSHCN home visit encounter summaries for more than half of each child's duration of medically fragile status were found in 67% of CSHCN charts, 50% of DCBS charts, but in none of the MCO charts.

Study strengths include a 58% response rate for the RC Survey; the use of a validated RC Survey instrument (Gittel, 2012); a representative sample of medically fragile children for chart review, with 95% of charts provided and accurate in terms of MCO membership; contract language as a basis for the definition of a service plan; DMS consensus regarding forms to use for medical record review; and evidence-based definitions of complex and medically fragile conditions (Burns *et al.*, 2010; Feudtner *et al.*, 2000; Simon *et al.*, 2010).

Study limitations for the chart review include the possibility that the services were undocumented, rather than not rendered; for example, CSHCN records with IHCP forms without signatures due to upload of signature images to an electronic system. Services rendered may have been documented in a manner inconsistent with study definitions; for example, those DCBS records with service plans that did not meet the current study definition of a collaborative service plan (e.g., Physical and Behavioral Health Service Plan, Initial Physical and Behavioral Health History [DPP 106B]), as well as the use of different service plan forms over time. In addition, for the chart review sample, the calculation of the number of months with active medically fragile status during the period from July 1, 2013 to June 30, 2014 was based upon the fields "approval date" and "release date;" and therefore, any inaccuracies of this data may have resulted in misclassification of a child as medically fragile for a minimum of six months during the study period. In addition, encounter file data on race was not provided for 29% of medically fragile children, and thus, limited characterization of this population. Finally, this study limited utilization management review to service denials, and did not assess service delays, another important consideration in light of the RC Survey findings.

Conclusions

Opportunities for MCO care/case managers to more actively engage in care management of medically fragile children merit collaborative exploration. Extreme concern regarding excessive caseload was the barrier identified by the greatest percentage of DCBS social workers/case managers and, to a lesser extent, by CSHCN nurses, but was not of comparable concern among MCO care/case

managers. Rather, lack of access to the foster parent was the prime concern of MCO care/case managers. Thus, collaborative exploration of means for enhanced engagement of MCOs in the care management process may alleviate workload burden for DCBS and CCSHCN, as well as facilitate MCO contact with the child's care coordination team, from foster parent to PCP and specialist physicians to DCBS case managers and CCSHCN nurses. Gaps in relational care coordination pertinent to initial engagement merit consideration as gateway challenges to address.

First, the low RC ranking of PCPs and specialist physicians by all workgroups indicates the need to engage physicians as part of the care coordination team.

Second, access to and availability of physicians is a related gateway challenge, as evidenced by the care coordination team's extreme concern regarding inability to find a provider within the area, inability to find a knowledgeable provider, and inability to find a provider who accepts insurance, highlighting the need to improve access to needed care for medically fragile children. National data suggest that children in foster care are particularly vulnerable to unmet need for health screening (Levinson, 2015). Of note, findings from the 2014 Access and Availability Behavioral Health Survey (IPRO/DMS, 2014) confirmed barriers to access: the overall compliance rate of 10.3% was substantially below the standard of 80% for provider access and availability.

Third, in order to collaboratively determine each child's medical needs and identify the need for placement in case management, each child in foster care is required to have a service plan prepared by DCBS and forwarded to the MCO, with DCBS and the MCO signatures indicating agreement with the plan. Yet, only 2% (2) charts included evidence of such initial RC.

Fourth, extreme concern regarding health plan denial of authorization for needed care/services was tied with excessive caseload as the top barrier overall (35%), with the greatest proportion of extremely concerned survey participants among CCSHCN Foster Care Support nurse consultants (47%). Of the 105 medically fragile children in the final chart review sample, 20% were denied service authorizations for at least one provider-requested service. The finding that adolescents diagnosed with co-morbid behavioral health problems and diabetes and who had psychiatric level of care denials that comprised the largest group (33%) emphasizes the challenges of care management for this vulnerable subpopulation. Typical clinical scenarios entailed self-harm behaviors enabled by the member's diabetic condition, e.g., non-compliance with insulin use and/or dietary restrictions, and

consequent psychiatric hospitalization. Each MCO had at least one member with this type of denial. Of note, authorization delays represent another important barrier that merits further exploration. Fifth, possible gaps in identification of medically fragile children were suggested by utilization profiles of high-risk children in foster care; that is, children who have at least one complex chronic condition (CCC), as well as hospital use patterns indicative of medical instability, i.e., two or more ED visits and two or more hospitalizations. Seventy percent of these high-risk children in foster care were not designated as medically fragile. Among high-risk children in foster care, these possibly “missed” children comprised 67% of children with 50 or more hospital days during the study period, 61% children with 8–26 ED visits, and 60% of children who received care from 3–6 specialty providers.

Recommendations for DMS, MCOs, DCBS and CCSHCN

The following five recommendations are based upon the “gateway challenges” identified in this study:

Recommendation #1: As recommended in the 2014 Access and Availability Behavioral Health Survey, DMS should continue to work with the MCOs to correct the reasons behind the low contact and appointment rates. Future surveys are recommended to assess compliance with access and availability standards specifically for the medically fragile subpopulation, for access to both physical and behavioral health providers. MCOs should assess their networks’ and providers’ availability with input from case managers, as well as access and availability survey findings, in order to develop strategies to access provider types found to be challenging for both “secret shoppers” and case managers.

Recommendation #2: As a first step toward improved RC, it is recommended that DMS convene a collaborative workgroup of lead MCO, DCBS and CCSHCN care/case managers to identify the specific provider specialty types with barriers to access by medically fragile children. Access and availability of primary care (e.g., Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services), specialty referral and care coordination services provided by the Thomas H. Pinkstaff Medical Home Clinic (Lexington, Kentucky) to medically fragile children, as well as the need for expansion of medical home services, merits further research. The proposed collaborative workgroup should consider how these services might be better incorporated into the medically fragile care coordination process, and develop strategies to enhance PCP and specialty provider engagement.

Recommendation #3: It is recommended that an additional charge of the collaborative workgroup be to develop a process and associated communication tools (e.g., collaborative service and care plans) for the initiation and ongoing monitoring of collaborative case management. The collaborative workgroup should consider a process for establishing a lead care coordinator to ensure effective and efficient communication across workgroups, and thus, address the issue of “who coordinates the coordinators” (Span, 2015).

Recommendation #4: The subset of medically fragile children with co-morbid behavioral health problems and diabetes merits consideration as a starting point for focused quality improvement efforts to be conducted by the collaborative workgroup. Engagement of PCPs and specialist physicians in the care coordination process to improve transitions from inpatient to outpatient services should be a critical component of this effort (O’Connell, 2014), with use of an actionable care plan collaboratively developed and implemented by the entire care coordination team, including PCPs and specialist physicians, consistent with the American Academy of Pediatrics (AAP) Policy Statement for Patient- and Family-Centered Care Coordination (AAP, 2014).

Recommendation #5: Findings suggest a possible role for MCO care/case managers in medically fragile case finding, and thus, an additional area of initial focus for the collaborative workgroup. A complementary process would entail DCBS’s review of the existing case finding processes and criteria in order to dovetail case finding efforts by MCOs with those of the DCBS Medical Support Section.

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Appendix A. ICD-9 Code Specifications for Complex Chronic Conditions

Table A1. ICD-9 Code Specifications for Complex Chronic Conditions

Complex Chronic Condition (CCC) Description and ICD-9 Code Specifications ¹
Brain and spinal cord: 740.0–742.9
Mental retardation: 318.0–318.2
Central nervous system degeneration and disease: 330.0–330.9, 334.0–334.2, 335.0–335.9
Infantile CP: 343.0–343.9
Muscular dystrophies and myopathies: 359.0–359.3
Heart and great vessel malformations: 745.0–747.4
Cardiomyopathies: 425.0–425.5, 429.1
Conduction disorders: 426.0–427.4
Dysrhythmias: 427.6–427.9
Cardiac: Aggregate Grouping of: Heart and great vessel malformations: 745.0–747.4 , Cardiomyopathies: 425.0–425.5, 429.1, Conduction disorders: 426.0–427.4 , and Dysrhythmias: 427.6–427.9
Respiratory malformations: 748.0–748.9
Chronic respiratory disease: 770.7
Cystic fibrosis: 277.0
Renal congenital anomalies: 753.0–753.9
Chronic renal failure: 585
Gastrointestinal congenital anomalies: 750.3, 751.1–751.3, 751.6–751.9
Chronic liver disease and cirrhosis: 571.4–571.9
Inflammatory bowel disease: 555.0–556.9
Sickle cell disease: 282.5–282.6
Hereditary anemias: 282.0–282.4
Hematologic or immunologic hereditary immunodeficiency: 279.0–279.9, 288.1–288.2, 466.1
Hematologic or immunologic acquired immunodeficiency: 042
Amino acid metabolism: 270.0–270.9
Carbohydrate metabolism: 271.0–271.9
Lipid metabolism: 272.0–272.9
Metabolic storage disorders: 277.3–277.5
Other metabolic disorders: 275.0–275.3, 277.2, 277.4, 277.6, 277.8–277.9
Chromosomal anomalies: 758.0–758.9
Congenital bone and joint anomalies: 259.4, 737.3, 756.0–756.5
Congenital diaphragm and abdominal wall anomalies: 553.3, 756.6–756.7
Other congenital anomalies: 759.7–759.9
Malignant neoplasms: 140.0–208.9, 235.0–239.9

¹As originally identified in Feudtner *et al.* (2000) and referenced by Burns *et al.* (2010) and Simon *et al.* (2010).

Appendix B. Specific Diagnoses of Interest with ICD-9 Coding Specifications

Table B1. Specific Diagnoses of Interest with ICD-9 Coding Specifications

Diagnoses of Interest ¹ with ICD-9 Code Specifications
Attention deficit disorder: 314.0
Asthma: 493
Autistic disorder: 299.0
Bipolar disorder: 296.0–1, 296.4–8
Cleft palate and cleft lip: 749
Congenital musculoskeletal deformities of skull, face and jaw: 754.0
Coagulation defects: 286
Congenital musculoskeletal deformities of spine (scoliosis): 754.2
Spina bifida: 741
Conduct disturbance: 309.3, 309.4, 312
Chronic Obstructive Pulmonary Disease (COPD): 490–492, 494–496
Depression: 296.2–3, 298.0, 300.4, 301.12, 309.0, 309.1, 311, 313.1
Diabetes: 250
Failure to thrive: 779.34, 783.41
Specific nonpsychotic mental disorders due to brain damage: 310
HIV: 042
PTSD: 309.81
Schizophrenia: 295
Epilepsy and recurrent seizures: 345
Congenital central alveolar hypoventilation syndrome: 327.25
Other congenital anomalies of upper alimentary tract: 750.xx
Obstructive sleep apnea: 327.23
Shaken baby syndrome: 995.55
Drug withdrawal syndrome :779.5
Fetal alcohol syndrome:760.71
Esophageal reflux:530.81
Blindness:369.0
Disturbance of emotions specific to childhood and adolescence: 312.xx, 313.xx
Episodic mood disorders: 296.xx
Delusional disorders and other nonorganic psychoses: 297.xx, 298.xx
Pervasive developmental disorders: 299.xx

¹Diagnoses of interest identified from the following sources: DMS Medically Fragile Training Program, Medically Fragile Designation Tip Sheet, IPRO/DMS Behavioral Health Population Focused Study, and preliminary chart review of initial 35 charts submitted for the current study conducted on 2/13/15.

Appendix C. Definition of Provider Types

Table C1. Provider Types

Provider Specialty Descriptions and Codes		Primary Care Descriptions and Codes		
Description	Provider Specialty Code	Description	Provider Type Code	Provider Specialty Code
Behavioral health		Primary care	31	
Psychiatric	011	General pediatrician		345
Psychologist	112	Family practitioner		316
Health service Provider in Psychology	114	Primary care		382
Psychiatric nurse	117	General practitioner		318
Family counselor	119	General preventive care		201
Licensed practical counselor	121	Internist		322
Psychiatrist	339	Family nurse practitioner		092
		Nurse practitioner (clinic)		084
		Nurse Practitioner (other)		093
		Physician assistant		100
Rehabilitation	013			
Podiatrist	140, 575			
Chiropractor	150			
Brain injury	179			
High risk pregnant women	214			
Oral surgeon	272			
Allergist	310			
Cardiologist	312			
Cardiovascular surgeon	313			
Dermatologist	314			
Gastroenterologist	317			
General surgeon	319			
Hand surgeon	321			
Neonatologist	323			
Nephrologist	324			
Neurological surgeon	325			
Neurologist	326			
Nuclear medicine	327			
Oncologist	329			
Ophthalmologist	330			

Provider Specialty Descriptions and Codes		Primary Care Descriptions and Codes		
Description	Provider Specialty Code	Description	Provider Type Code	Provider Specialty Code
Orthopedic surgeon	331			
Otolaryngologist	332			
Pediatric surgeon	334			
Physical medicine	336			
Plastic surgeon	337			
Proctologist	338			
Pulmonologist	340			
Thoracic surgeon	342			
Urologist	343			
Neuroradiology	349			
Endocrinologist	350			
Infectious disease	351			
Transplant hepatology	353			
Pain medicine	354			
Medical genetics	356			
Neurodevelopmental disabilities	357			
Neuropathology	358			
Medical toxicology	359			
Sleep medicine	536			
Hematology	537			
Reproductive endocrinology	538			
Interventional pain management	539			

Appendix D. Relational Coordination Survey Report: Coordination of Care for Medically Fragile Foster Care Children Enrolled in Medicaid Managed Care



KDS RC Survey
detailed results repor

Appendix E. Principal Hospital Diagnoses for Medically Fragile Children in Record Review

Table E1. Principal Hospital Diagnoses for Medically Fragile Children in Record Review

6: Hospitalizations attributed to: ^{1,2}	4: Hospitalizations for each of the following: ^{1,2}	3: Hospitalizations for each of the following: ^{1,2}	2: Hospitalizations for each of the following: ^{1,2}	1: Hospitalization for each of the following: ^{1,2}
DMI ketoacd (7.69%)	Bipol I crnt depress (5.13%)	Episodic mood disord (3.85%)	Neutropenia (2.56%)	Amino-acid transport dis ³ (1.28%)
	Acute kidney failure (5.13%)	Cong cntrl hypovent synd (3.85%)	Recur depr psych-severe (2.56%)	Hyperosmolality (1.28%)
	Failure to thrive-child (5.13%)	Epilep w/o intr epil (3.85%)	Bipolar disorder (2.56%)	Hb-SS disease w crisis (1.28%)
		Compl kidney transplant (3.85%)	Cannabis abuse-unspec (2.56%)	Bipol I single manic NOS (1.28%)
			Depressive disorder (2.56%)	Depress psychosis-severe (1.28%)
			Acute upr resp infection (2.56%)	Hyp kid NOS w cr kid V (1.28%)
			Dz of larynx Necrosis (2.56%)	Parox atrial tachycardia (1.28%)
			Asthma (2.56%)	Mucocutan lymph node syn (1.28%)
			Intestinal obstruction (2.56%)	Flu w resp manifest NEC (1.28%)
			Hypoplas left heart synd (2.56%)	Asthma w status asthmat (1.28%)
			Anomal skull/face bones (2.56%)	Other pulmonary insuff (1.28%)
				Esophageal reflux (1.28%)
				Neurogenic bladder NOS (1.28%)
				Idiopathic scoliosis (1.28%)
				Spinal cord anomaly NEC (1.28%)
				Perinatal infection NEC (1.28%)
				Neonat jaund preterm del (1.28%)
				NB drug withdrawal syndr (1.28%)
				Convulsions NEC (1.28%)
				Postprocedural fever (1.28%)
				Abn kidney funct study (1.28%)
				Disloc 2nd cerv vert-cl (1.28%)
				Subdural hem w/o coma (1.28%)
				Dialysis encounter, NEC (1.28%)
				Rehabilitation proc NEC (1.28%)
				Antineoplastic chemo enc (1.28%)

¹ n = 78 hospitalizations; this served as the denominator to calculate percentages. Live births occurring in the hospital were excluded from analysis (n = 2).

² Member-level data are not represented in this table, and thus medically fragile members in this sample with more than one hospitalization are counted multiple times.

³ Representative examples include alkaptonuria, homocystinuria, tyrosinemia, and phenylketonuria.