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Prescribed Pediatric Extended Care: A program evaluation on the impact to families of children with medical complexities.

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Prescribed Pediatric Extended Care (PPEC):

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Abstract

Background: Considering the barriers facing children with medical complexities (CMC), attention to family impact could have the greatest potential on CMC optimal health. **Prescribed Pediatric Extended Care (PPEC)**, established in 1983, is a program and intervention impacting families of CMC.

Purpose: The purpose of this project was to evaluate the impact of PPEC on families of CMC.

Methods: The Centers for Disease Control and Prevention (CDC) framework for program evaluation in public health was modeled in developing the design of the PPEC program evaluation. The project setting was a six-center, PPEC organization. The pediatric quality of life (PedsQL) Family Impact Module version 2.0 (FIM) was used as the survey tool for the program evaluation project.

Results: Dependent samples t-test findings showed total FIM scores (n=24) significantly improved ($p<.001$) from admission to PPEC ($m=55.05$, $SD=10.89$) to 60 days post-PPEC admission ($m=73.08$, $SD=16.29$).

Discussion: Family functioning scores (Daily Activities + Family Relationships) had the most statistically significant mean change after 60 days of PPEC services. The PPEC program evaluation will adjust based on project results to specifically review family functioning dynamics for longitudinal study.

Conclusion: PPEC appears to have a positive effect on family functioning.

Key terms: Prescribed Pediatric Extended Care, children with medical complexities, family impact, family functioning, parent health related quality of life, guardian caregiver.

Background

Children with medical complexities (CMC) are characterized by having chronic conditions typically identified and associated as medically fragile (**Table 1**). According to Cohen et al. (2011), these complex medical conditions involve multiple specialists, functional limitations (often resulting in technology dependence), family-identified substantial healthcare resource needs, and elevated, disparate utilization costs. The services necessary for CMC to reach their fullest potential are disproportionate to all other pediatric subsets and result in the highest medical care costs (Kuo & Houtrow, 2016). Although CMC account for fewer than 1% of all children in the United States, they represent greater than 30% of total pediatric health dollars spent (Lakhaney, Shaw, & Stockwell, 2021; Barnert et al., 2019; Berry et al., 2014).

The number of CMC is increasing at a rate of 5% per year and survivorship has contributed to a growing gap in resources and lack of care alternatives for families (Ferro et al., 2021, Gallo et al., 2021). The net result leaves the burden of care to families of CMC to provide care for their children who have lived beyond the scientific evidence used to guide their treatment or the current capacity of available resources (Allshouse et al., 2018). CMC survivors, families and caregivers have inadequate evidence-based models of care for out-of-the-hospital interventions to assist with the impact of caring for their CMC. Out of an emerging and increasing necessity, families and communities have had to take on the primary role of providing continuous, specialized intensive care interventions away from the hospital (Edelstein et al., 2016; Gallo et al., 2021). Consequently, half of all families of CMC report unmet medical needs, reduced employment, or family financial problems. Outcomes, such as poor family functioning, exhaustive hours providing direct care or coordination of care, family financial strain, missed work, increased emergency utilization or hospitalization, or difficulty accessing fragmented services routinely impact the health and functioning of the entire family unit. Thus, health and symptoms of CMC are in a continuous, interconnected, bi-directional relationship with the optimal health of the family (Kuo et al., 2011; Barnert et al., 2019).

The literature describing CMC acknowledges a vast, interdependent relationship between the health of the family and the CMC population. Although Barnert et al. (2019) found that 43% of articles included in their review of CMC had at least one outcome within their domain classified as family well-being, the authors emphasized studies examining outcomes further related to family impact (burden, well-being, quality of life, functioning, stress, time-burden, financial burden, self-efficacy, and communication) were still notably lacking. Research also suggests that CMC have the highest risk of all

children for adverse family outcomes and conflicts (Barnert et al., 2019). For purposes of this program evaluation, family refers to parents, relatives, and guardian caregivers. Family impact encompasses the concepts of family functioning, communication, worry, and parent health-related quality of life (PHRQOL).

Many factors have been shown to negatively impact families of CMC. Frequent healthcare encounters are associated with negative implications for families of CMC including family life disruptions, time off work, and increased financial pressures for out-of-pocket costs (Cohen et al., 2018; Kuo et al., 2018). Although reducing hospitalization and emergency department visits for CMC (which accounts for more than 50% of Medicaid's' total healthcare expenditures) is a key objective within the healthcare system, in doing so, the stress inadvertently and by default gets shifted back to the family (Coller et al., 2017). By avoiding hospitalizations and decreasing lengths of stay, larger degrees of burden are displaced onto the care support of those with CMC (Bradshaw et al., 2019). Caregivers can feel more stressed as the responsibility of care increases with greater burden in a tireless loop. For example, emergency department visits increase as care burden for CMC increases (Pulcini et al., 2021). Without alternatives to care outside of the hospital, stress and burden increase for families struggling to keep their child out of the hospital.

Consequently, the calculation of cost of care for CMC is confounded by this constant cycle of burden and cost shifting back to the families. Annual CMC health care costs are up to fourteen times higher to the family than costs of healthy children (Kuo et al., 2018). Research shows that one out of four hospitalizations could be avoided with CMC care that has a multidisciplinary team and nursing staff coordinating with a pediatric center to reduce future healthcare costs (Gallo et al., 2021). In terms of cost-effectiveness, real-time access to knowledgeable and familiar providers can reduce emergency department visits which lead to hospitalization and increased family impact and burden (Pulcini et al., 2021).

Kuo and Houtrow (2016) recommended that optimal care for CMC outside the hospital should also incorporate the life experience of the individual family into understanding the complexity of the child. The authors wrote that higher family satisfaction and higher family functioning can only be achieved through family-centered care. Proper access to care coordination is associated with higher caregiver health with fewer mentally unhealthy days (Yu et al., 2020). Caregiver physical health can be negatively impacted by the direct nature of the care they provide to their CMC. Family mental health can be challenged due to the amount of time and attention required and the pain of witnessing one's

child suffer (Desai et al., 2016; Kuo et al., 2011). One-fifth of parents of CMC (18.6%) report poor or fair mental health compared to (8.7%) parents of noncomplex children.

Families lacking out-of-the hospital interventions or models of care support have shown increased lost employment time, lost leisure time, higher levels of stress, marriage tensions and financial difficulties. Edelstein et al., (2016) suggested that targeted interventions and collaboration of CMC stakeholders can positively impact family-based outcomes, including family stress, health, and family functioning. Although CMC access to care outside of the hospital is not a variable often studied, as many as 75% of parents surveyed reported that they were struggling to meet the demands of parenting a CMC and did not know where to go for help in the community (Bayer et al., 2021).

Prescribed Pediatric Extended Care

Although evidence in the literature is sparse regarding specific interventions or models of care impacting families of CMC, Coller and Komatz (2020) identified prescribed pediatric extended care (PPEC) as an intervention to improve burden of care, functioning and support for families of CMC. PPEC was established in 1983 as an out-of-the-hospital access to care intervention for children and families impacted by a severe or chronic medical complexity. In 1985, the first standards of care for PPEC were published as the result of a grant from the Division of Maternal and Child health division, United States public health service (Pierce, Freedman, & Reiss, 1987).

PPEC is a community-based, non-residential, pediatric medical day treatment care delivery model that provides a comprehensive and coordinated triad of services (skilled nursing, caregiver training, and developmental care interventions) in a group setting (Kentucky Administrative Regulation, 2020; Coller & Komatz, 2020). PPEC functions as a link in the care continuum of a child who, because of medical condition, requires continuous skilled intervention prescribed by a primary care provider (PCP) and administered by or under the direct supervision of a licensed registered nurse (Pennsylvania Administrative Statutes, 1999; Minnesota Statutes, 2018; Kentucky Administrative Regulation, 2020). PPEC is designed as an out-of-the hospital alternative to in-home care, long-term institutional care, or residential care. PPEC delivers sophisticated medical technology interventions in an environment that fosters prevention of medical crisis, promotes developmental progress, accounts for burdens of care in a cost-effective manner, enhancing optimal family functioning (Pierce et al., 1987).

Although statutes vary, most PPEC state statutes and regulations require facilities to be equipped and staffed to accommodate and provide basic nonresidential services to three or more medically or technologically dependent children. Families of CMC considered for PPEC have needs that

require continual nursing management. The primary care provider is responsible for recommending placement in a PPEC only after medical, emotional, psychosocial, and environmental factors have been considered through family consultation (Kentucky Administrative Regulation, 2020).

Care is assessment driven, family-centered and designed jointly to meet the goals of the CMC. The care plan requires ongoing collaboration with family on a progress-oriented protocol of care highly specific and therapeutic to the CMC while also addressing family benefits and outcomes (Pierce et al., 1991). Continuity of care occurs within the program to prevent fragmentation, ensuring access to care, and enhancing caregiving skills and knowledge (Allshouse et al., 2018; Pordes et al., 2018; Pulcini et al., 2021). Pulcini et al. (2021) stated that a program with individualized care plans, multidisciplinary approach, and care coordination for CMC also can be associated with reduced emergency department visits. Seventy-five percent of parents in PPEC reported a reduction in unanticipated health care visits and costs (Pierce et al., 1991; Caicedo, 2013). Consequently, studies support PPEC benefits to the Medicaid health delivery care coordination system and cost-effectiveness which showed an estimated 20% reduction in the cost for an acute care setting and 66% reduction in the cost of in-home care or private duty nursing (Pierce et al., 1991; Caicedo, 2013). The assumption in cost savings comes from a service substitution for complex home nursing services and from offsets for hospital-related costs. However, no literature states PPEC would be at a lower overall cost (Minnesota Statutes Chapter, 2018).

Care coordination in PPEC is performed by a defined team focused on partnership, accessibility, familiarity, and early recognition. Pordes et al. (2018) stated that the advantage to models of care outside the hospital include proximity to a child's home, ability to care for other family members, and an understanding of the local culture and context to empower the community as well as the lives of CMC. Children and guardians in PPEC have been shown to have the highest health-related quality of life, including physical and psychosocial functioning, overall, when compared to private duty nursing or long-term care (Caicedo, 2013). Providing care for CMC is recognized in the literature as challenging, and a strain on current or absent family resources. Innovative programs and alternatives to home or long-term care settings, such as PPEC, have emerged to address the barriers to access of care impacting families of CMC. Despite the recommendation from the Pediatric Complex Care Association to develop more community-based services such as PPEC nationwide, a deficit in PPEC programs and community-based alternatives still exists (Pediatric Complex Care, White paper, 2016).

The PPEC program evaluation assesses the impact, effectiveness, and outcomes of the PPEC organization by using quantitative, descriptive indicators to calculate and emphasize family impact

through parent-reported health-related quality of life (PHRQOL) and family functioning. There is not a sufficient research base to determine if PPEC is an evidence-based care solution for families of CMC. Nevertheless, Harrigan, Ratliffe, Patrinos, and Tse (2002), stated that community based, pediatric extended care facilities may be a means of reducing cost, improving physical and developmental outcomes through coordinating care, as well as minimizing family stress and burden of care.

Purpose Statement

This program evaluation project evaluates the family impact of PPEC. Research suggests that attention to family impact can have meaningful effect on outcomes of CMC (Yu et al., 2020). This project focuses on quantifying family impact of PPEC as an out-of-the-hospital, model of care and intervention available for families of CMC. Through utilizing a specific family impact survey, a total family impact score was collected and analyzed to indicate better or poorer family functioning and PHRQOL prior to beginning PPEC services, and after PPEC model of care was prescribed and utilized for more than 60 days.

Project Design

Theoretical Framework

Centers for Disease Control and Prevention (CDC) framework for program evaluation in public health was adapted as the model in developing the design of the PPEC program evaluation (**Appendix A**). The essential elements of the model served as a template to design an optimal, context-sensitive impact evaluation which included the following steps: engaging stakeholders, describing the program, focusing on the evaluation design, gathering credible evidence, justifying conclusions, ensuring use, and sharing lessons learned (CDC, 1999). The framework helped the PPEC program to structure the strategy in which family impact of care was reviewed, analyze how the program operated, and develop future expectations or standards of PPEC care delivery and family consideration. The central public health standards of the CDC framework (utility, feasibility, propriety, and accuracy) were considered throughout project stages. The PPEC evaluation team (PET) meetings were conducted throughout the project to reexamine the design of the program evaluation and plan for improvements and adjustments. The PPEC program evaluation was based on the CDC framework to maximize prospective effectiveness of the family impact data collected, as well as to avoid creating an imbalance in any one dimension of the framework potentially compromising the project (CDC, 1999).

Project site and Population

The project setting was a six-center, PPEC organization in the southeastern United States. Each PPEC center served as a project evaluation site and followed administrative regulations and enforcement of state PPEC standards to implement all provisions of care (Kentucky Administrative Regulations, 902, 20:280, 2018). The survey population consisted of caregivers of CMC at one of the six centers. All PPEC children were between 0-21 years of age, with varying diagnoses and degrees of medical complexity, referred by a primary care physician and were recipients of federally mandated early periodic screening, diagnosis, and treatment (EPSDT), through Medicaid managed care services.

Measures

The pediatric quality of life (PedsQL) Family Impact Module version 2.0 (FIM) was used as the measurement tool for the project (**Appendix B**). The FIM measures caregivers' own quality of life and the impact of pediatric chronic health conditions on overall family functioning (Varni et al., 2004; Fitzpatrick et al., 2020). The FIM includes thirty-six items measuring caregiver quality of life across eight dimensions with higher scores indicating increased family functioning and efficacy (Fitzpatrick et al., 2020). The model that guided the development of the FIM, indicates caregiver physical functioning (PFS), emotional functioning (EFS), social functioning (SFS), cognitive functioning (CFS), communication (CS), worry (WS), daily activities (DAS), and family relationships (FRS) are impacted by their child's chronic health condition (**Table 2**). The FIM consists of Likert type, five-point response scales (ranging from "never a problem" to "almost always a problem") that are reverse scored and linearly transformed (0=100, 1=75, 2=50, 3=25, 4=0) to calculate mean total summative scores for each dimension of impact. Twenty items comprise the dimensions for parent health-related quality of life (PHRQOL), while the eight items primarily attributed to communication and worry are scored individually (Fitzpatrick et al., 2020). An overall family functioning summary score (FFS) is also computed from the eight items questioning daily activities and family relationships.

The FIM has been found highly reliable and sensitive with strong internal consistency (Cronbach alpha =0.97) in measuring these parameters in all studies reported using the FIM (Varni et al., 2004). For this program evaluation project, the FIM was adapted to a digital form for participants to interface on tablet or mobile applications (**Appendix C**). Although only the English and Spanish written versions were used in this project, the Family Impact Module version 2.0 (FIM) has been translated into over seventy languages (Varni, 2021).

Methods

Program Evaluation Team Formation

A PPEC evaluation team (PET) was convened by the PPEC organization to conduct the program evaluation. The PET consisted of the organization's Chief Medical Officer, Chief Nursing Officer, Director of Nursing Operations, PET project site nurses, and discharged PPEC program participants and family members. All conflicts of interests and rights of human subjects were disclosed at time of PET formation and prior to project implementation. The PPEC organization's board of trustees was consulted to address systematic standards before the PET was assigned to tasks or activities. Institutional Review Board (IRB #1000) approval and exemption was obtained prior to project implementation. The FIM was a part of the program evaluation admission process for all caregivers of CMCs at one of the six centers prior to implementation of this program evaluation project.

The principal stakeholder groups engaged with data included: the staff within each PPEC setting (program evaluation project site) and those surveyed about PPEC as an intervention impacting their family. Other data sources involved with the project included the PPEC Evaluation Team (PET) that gathered and collected evidence, the primary users of the program evaluation (management, organizational board, and PPEC industry leaders or interest groups), and the survey participants (guardian caregivers) impacted by care received from the PPEC.

Data Collection

Informed and written consent was obtained from all participants in the PPEC program evaluation. Family respondents for the FIM consisted of guardians of CMC who were offered the survey opportunity upon admission, provided an opportunity to opt out of the survey at any time, and were informed of the follow-up survey that would be administered >60 days after admission. Families were assigned to PET nurses who were responsible at each program evaluation project site to explain, help, and guide guardian caregivers taking the FIM. PET nurses administered the FIM as trained project specialists having at least two years nursing experience, of which at least six months were spent as a PPEC registered nurse (RN). Each implementation site PET nurse was prepared with intimate knowledge of the FIM survey and program evaluation process through educational offerings, awarded credibility as a representative through the organization's proprietary clinical ladder system, and deemed an expert by the PPEC organization after 24 hours of continuing education and competency related to PPEC standards and regulations, FIM project measurement tool, or project framework for program evaluation. The PET consistently focused and readjusted as the project progressed on the central steps of the CDC

framework (utility, feasibility, propriety, and accuracy) to assess, adapt, and change as necessary to achieve these pragmatic standards incrementally throughout the project implementation (CDC, 1999).

Guardian caregivers were given the option of taking the FIM on an automated interface within the project setting or leaving a hard copy in an envelope marked for their use. PET project site nurses collected FIM summative scores upon admission to each PPEC setting. Families were admitted and began receiving PPEC services for CMC. The PET nurses then collected FIM summative scores after sixty days of PPEC intervention.

All information and data collected was kept strictly confidential and stored in a secure, safe repository. Data for this program evaluation project was labeled with internal numeric identifiers. Family identities were protected and remained separate from project data through de-identification by a second numeric number. The data was then entered into Microsoft Excel and imported into the Statistical Package for the Social Sciences (SPSS IBM version 27.0) for analysis.

Analysis

The PET collected descriptive demographic data from family respondents including PPEC setting location (center), age of CMC (in months), CMC gender, CMC acuity level (I-IV), and relationship of survey respondent (mother, father, grandparent, or other guardian caregivers). PPEC acuity level is an ordinal level of measurement set during admission by utilizing a PPEC Acuity Leveling Evaluation Tool and (LET) scorecard from the Kentucky Cabinet for Health and Human Services (**Appendix D**) (Kentucky Administrative Regulation - PPEC, 2020). Data for descriptive statistics were analyzed by calculating means and standard deviations for continuous data, and frequencies for nominal and ordinal data.

The Mean total FIM scores were computed using the FIM scoring guidelines. Next, a parent health-related quality of life (PHRQOL) summary score (20 items: physical - 6 items, cognitive - 5 items, emotional - 5 items, social - 4 items) and a family functioning summary score (FSS - 8 items: daily activities - 3 items, family relationships - 5 items), were calculated. Family communication (CS - 3 items) and worry (WS - 5 items) dimensions are independent scores reflecting family burden and were therefore, kept separate in this data file, but could be summed together to create a caregiver quality of a life score (Fitzpatrick et al., 2020).

To evaluate the program's effectiveness in improving health related quality of life among caregivers of CMCs enrolled in PPEC, a dependent sample T-test was conducted to determine if there was a significant increase in mean total FIM scores after 60 days of PPEC enrollments compared to admission FIM scores**.** Data were paired using the deidentified number assigned by the PET staff.

Dependent samples T-tests were then performed on mean dimension scores to determine where specific improvements occurred.

Results

Participants included twenty-four guardian caregivers (n=24) of CMC admitted to PPEC between December 2021 and April 2022, out of the eighty total admissions during that period. Eight respondents utilized paper FIM surveys, with the remainder completing automated tablet interfaces. Two families completed electronic Spanish versions of the FIM. Descriptive statistics revealed that CMCs ranged from 3-132 months, with a mean age of 25.8 months. The majority of CMC's reported on were boys (n=18), and most guardian caregivers were mothers (n=18) (**Table 3**).

Summative FIM scores after PPEC intervention were significantly improved over those obtained prior to PPEC ($p<.001$). The findings of this program evaluation project showed that total FIM scores positively increased from before receiving PPEC services (M=55.05, SD=10.89) to after >60 days of PPEC (M=73.08, SD=16.29). Follow-up dependent samples T-tests also found a statistically significant increase in all FIM summative scores (**Table 4**).

Parent health-related quality of life (PHRQOL) was significantly improved after PPEC was utilized, despite physical functioning (PSS1-PSS2 = <.001) being the only dimension withing PHRQOL that was significantly improved. Social, emotional, and cognitive dimensions were not significantly changed. Communication summative scores (CS1 and CS2) were the least changed and did not affect any other cumulative scores as they stood alone. Daily activities (DAS1 fand DAS2) and family relationships (FRS1 and FRS2) significantly improved.

Discussion

The results demonstrated PPEC services and care may have an impact on families. Family functioning scores (Daily activities + Family relationships) had the greatest and most statistically significant mean change after 60 days of PPEC services. While the sample size is small, it provides a justification for further study and continued collection of data. The PET team will reexamine the results of the project to adjust the PPEC program evaluation based on the central components (utility, feasibility, propriety, and accuracy) of the CDC framework (CDC, 1999). Daily activities will be separated and reviewed based on PPEC best practices, care coordination, and parent notification and documentation. Family relationships data will be examined for correlation between household or PPEC plan of care. Household family structure including marital status, number of members in the household, and natural, adoptive, or foster parent status will also be collected as an adjustment resulting from Family Functioning Scores (FFS).

Worry (WS) will be analyzed as its' own dimension in the program evaluation to determine the role PPEC plays in lessening worry for families of CMC. Any additional data (ED visits/hospitalizations, unanticipated medical emergencies, deaths, and unanticipated decreases in acuity levels) will continue to be collected and recorded for the project cohort (n=24) as part of the PPEC program evaluation. Cost of care, perceived care coordination while at the PPEC, loss of work, and other factors affecting the guardian caregiver's burden of care data will continue to be collected for a long-term longitudinal study with potential regression analysis related to diagnosis and severity.

Although the CDC Framework for PPEC program evaluation allows for constant readjustment as a plan for addressing unintended and unanticipated consequences, limitations existed during this project. First, the response rate was much lower than anticipated (30%). Consequently, the same reasons guardian caregivers provided for not participating in the survey or for their opting out, are the same dimensions the FIM wished to study. Nevertheless, a more conducive ability and timeframe to take the FIM could be explored to help the number of guardian caregivers who choose to participate. Second, it is difficult to conclude that the PPEC program, rather than an unmeasured variable, caused the observed changes. Third, surveys were not solicited and collected from new admissions in every instance as planned. For instance, the data does not explain why one PPEC setting accounted for one-third of the admission surveys when other centers had more new CMC admissions during the project timeframe. FIM scores could vary based on differences in data collection within each center. Finally, guardian caregiver information will be expanded with the planned longitudinal program evaluation.

Conclusion

The purpose of this project was to evaluate the impact of PPEC on families of children with medical complexities (CMC). It is crucial that the healthcare system understand how PPEC may impact families of CMC to find solutions that can effectively improve out-of-the-hospital access to care and subsequently reduce risks and gaps in the care of CMC and their families. Although quality of life (QoL) research is descriptive, family functioning with CMC care in an alternative, out-of-the-hospital program such as PPEC has yet to be described in detail. Nevertheless, PPEC seems to have a positive effect on family functioning. The PPEC organization performing the program evaluation will utilize FIM data as the focus for future program outcomes. Currently, twelve states have regulations published in their state or commonwealth health plans to support PPEC (Table 5.).

Potential Future Studies

Families, parents, and guardian caregivers of CMC need more alternatives to home-based or hospital care. More community-based care options and intervention developments must be created to

address the gaps in care affecting families of CMC. Careful tailoring of interventions accessible across the complexity spectrum are necessary to relieve the burden of care for guardians and families of CMC. PPEC is in a unique position in the community to address these gaps in care, and to solve access to care shortfalls related to cost, care coordination, and burden or impact of care on the family. PPEC can participate in care integration, prevention, promotion, and upstream solution strategies to assist family impact, functioning and parent health-related quality of life.

The PPEC program evaluation is continuing a long-term longitudinal cohort and the results of this project will be used to generate future PPEC studies. The potential benchmarks and outcomes uncovered in this program evaluation, evidence-based practice guidelines or even a balanced scorecard template could be developed from this project for other PPEC organizations or PPEC research. The next steps in the program evaluation will be to formulate a PPEC Logic Model as a graphic depiction or road map to represent the shared relationships between the current program and the program activities or elements versus the intended effects. A PPEC Logic Model will construct how PPEC facilities are supposed to work, benchmarks for future programs, and itemized and published industry standards. The PPEC Logic Model will assist in the development of a PPEC blueprint for organizational change, determine the overall evaluation on family impact, and disclose and disseminate program evaluation findings to the stakeholders.

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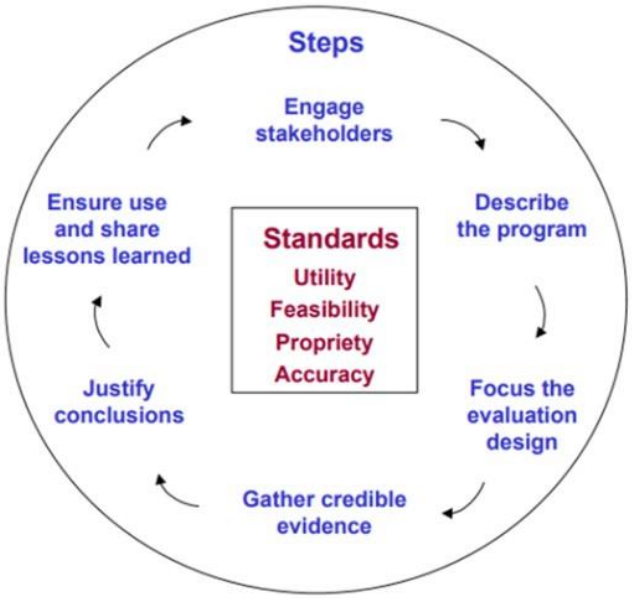
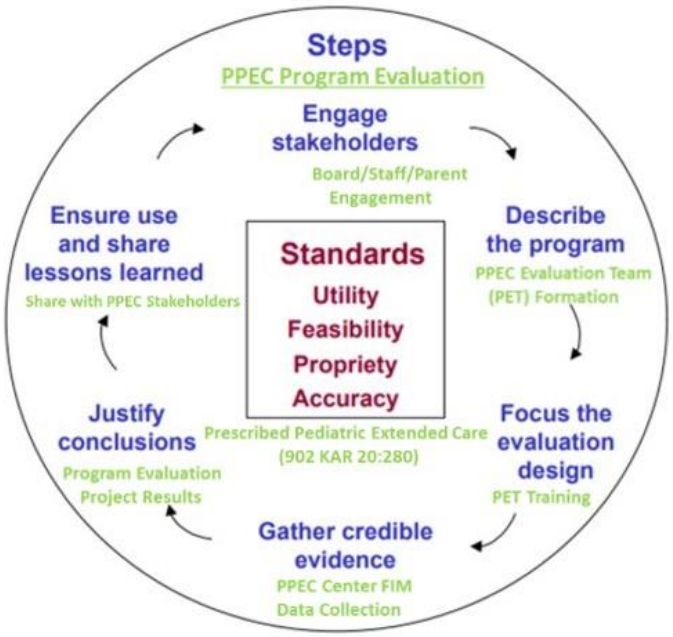
Appendix A

Adapted CDC Framework for PPEC Program Evaluation



(Centers for Disease Control and Prevention, 1999)



Appendix B

PedsQL Family Impact Module (FIM)

PedsQL™
Family Impact Module

Version 2.0

PARENT REPORT

DIRECTIONS

Families of children sometimes have special concerns or difficulties because of the child's health. On the following page is a list of things that might be a problem for **you**. Please tell us **how much of a problem** each one has been for **you** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

PHYSICAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel tired during the day	0	1	2	3	4
2. I feel tired when I wake up in the morning	0	1	2	3	4
3. I feel too tired to do the things I like to do	0	1	2	3	4
4. I get headaches	0	1	2	3	4
5. I feel physically weak	0	1	2	3	4
6. I feel sick to my stomach	0	1	2	3	4

EMOTIONAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel anxious	0	1	2	3	4
2. I feel sad	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I feel frustrated	0	1	2	3	4
5. I feel helpless or hopeless	0	1	2	3	4

SOCIAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel isolated from others	0	1	2	3	4
2. I have trouble getting support from others	0	1	2	3	4
3. It is hard to find time for social activities	0	1	2	3	4
4. I do not have enough energy for social activities	0	1	2	3	4

COGNITIVE FUNCTIONING *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to keep my attention on things	0	1	2	3	4
2. It is hard for me to remember what people tell me	0	1	2	3	4
3. It is hard for me to remember what I just heard	0	1	2	3	4
4. It is hard for me to think quickly	0	1	2	3	4
5. I have trouble remembering what I was just thinking	0	1	2	3	4

COMMUNICATION *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel that others do not understand my family's situation	0	1	2	3	4
2. It is hard for me to talk about my child's health with others	0	1	2	3	4
3. It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

PedsQL 3

*In the past **ONE month**, as a result of your child's health, how much of a problem have **you** had with…*

WORRY *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I worry about whether or not my child's medical treatments are working	0	1	2	3	4
2. I worry about the side effects of my child's medications/medical treatments	0	1	2	3	4
3. I worry about how others will react to my child's condition	0	1	2	3	4
4. I worry about how my child's illness is affecting other family members	0	1	2	3	4
5. I worry about my child's future	0	1	2	3	4

DIRECTIONS

Below is a list of things that might be a problem for **your family**. Please tell us **how much of a problem** each one has been for **your family** during the **past ONE month.**

*In the past **ONE month**, as a result of your child's health, how much of a problem has **your family** had with…*

DAILY ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Family activities taking more time and effort	0	1	2	3	4
2. Difficulty finding time to finish household tasks	0	1	2	3	4
3. Feeling too tired to finish household tasks	0	1	2	3	4

FAMILY RELATIONSHIPS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. Lack of communication between family members	0	1	2	3	4
2. Conflicts between family members	0	1	2	3	4
3. Difficulty making decisions together as a family	0	1	2	3	4
4. Difficulty solving family problems together	0	1	2	3	4
5. Stress or tension between family members	0	1	2	3	4

Appendix C

Adapted Family Impact Module (FIM)

PedsQL Family Impact Module 2.0

The Kidz Club (TKC) is interested in learning more about the families that we serve. We want to know how the care that we provide not only impacts our children, but also their parent or guardian. TKC understands that families and guardians of children with medical complexities have unique concerns and difficulties related to their child's health. In the survey you will find topics that may be a problem you have faced. Please tell us how much of a problem each of these topics has been for you during the past month. There are no right or wrong answers, so please answer as honest as possible. Protection of information disclosed in addition to ethical considerations will be maintained throughout the duration of this research study. If you do not understand a question, please ask a member of the Leadership Team for help. We value and appreciate your feedback.

* Required

PedsQL Family Impact Module 2.0

Families of children sometimes have special concerns or difficulties because of the child's health. On the following pages is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month choosing:

0 if it is never a problem
1 if it is almost never a problem
2 if it is sometimes a problem
3 if it is often a problem
4 if it is almost always a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

1. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

.....PH

YSICAL FUNCTIONING (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always
I feel tired during the day	◯	◯	◯	◯	◯
I feel tired when I wake up in the morning	◯	◯	◯	◯	◯
I feel too tired to do the things I like to do	◯	◯	◯	◯	◯
I get headaches	◯	◯	◯	◯	◯
I feel physically weak	◯	◯	◯	◯	◯
I feel sick to my stomach	◯	◯	◯	◯	◯

2. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

.....EM

OTIONAL FUNCTIONING (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
I feel anxious					
I feel sad					
I feel angry					
I feel frustrated					
i feel helpless or hopeless					

3. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

.....

SOCIAL FUNCTIONING (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
I feel isolated from others					
I have trouble getting support from others					
It is hard to find time for social activities					
I do not have enough energy for social activities					

4. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

COGNITIVE FUNCTIONING (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
It is hard for me to keep my attention on things					
It is hard for me to remember what people tell me					
It is hard for me to remember what I just heard					
It is hard for me to think quickly					
I have trouble remembering what I was just thinking					

5. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

.....CO

MMUNICATION (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
I feel that others do not understand my family's situation	◯	◯	◯	◯	◯
It is hard for me to talk about my child's health with others	◯	◯	◯	◯	◯
It is hard for me to tell doctors and nurses how I feel	◯	◯	◯	◯	◯

6. In the past ONE month, as a result of your child's health, how much of a problem have you had with...

.....W

ORRY (Problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
I worry about whether or not my child's medical treatments are working	◯	◯	◯	◯	◯
I worry about the side effects of my child's medications/medical treatments	◯	◯	◯	◯	◯
I worry about how others will react to my child's condition	◯	◯	◯	◯	◯
I worry about how my child's illness is affecting other family members	◯	◯	◯	◯	◯
I worry about my child's future	◯	◯	◯	◯	◯

Directions: Below is a list of things that might be a problem for your family. Please tell us how much a problem each one has been for your family during the past ONE month.

7. In the past ONE month, as result of your child's health, how much of a problem has your family had with...
.....DAILY ACTIVITIES (problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
Family activities taking more time and effort	◯	◯	◯	◯	◯
Difficulty finding time to finish household tasks	◯	◯	◯	◯	◯
Feeling too tired to finish household tasks	◯	◯	◯	◯	◯

8. In the past ONE month, as result of your child's health, how much of a problem has your family had with...

.....FAMILY RELATIONSHIPS (problems with...) *

Mark only one oval per row.

	0 (Never)	1 (Almost Never)	2 (Sometimes)	3 (Often)	4 (Almost Always)
Lack of communication between family members	◯	◯	◯	◯	◯
Conflicts between family members	◯	◯	◯	◯	◯
Difficulty making decisions together as a family	◯	◯	◯	◯	◯
Difficulty solving family problems together	◯	◯	◯	◯	◯
Stress or tension between family members	◯	◯	◯	◯	◯

Reference

https://www.pedsql.org/

Appendix D

PPEC Acuity Leveling Evaluation Tool (LET)

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)

Child's Name		**Dates of Service:**		
Reviewer's Name		**Reviewer's Title:**		
Reviewer's Signature				
Level I Services Standard Points[1]	**Total**			**12 Points**
	1 Point	2 Points	3 Points	4 Points
Additional Health Assessment				
Not Included Elsewhere (based on current diagnosis and/or signs and symptoms within at least the past 12 months)	X[2]	M[2]	W[2]	D[2]
	Please specify system, diagnosis and/or signs & symptoms:			
Respiratory				
Respiratory Assessment (based on current diagnosis and/or signs and symptoms within the past 12 months)	As needed (Adverse Respiratory Condition), X[2]	M[2]	W[2]	D[2]
Breathing Treatment/ Bronchodilator	As needed (Up to two/week)	Daily/as needed (Up to two/day)	Daily/as needed (Up to four/day)	Daily/as needed (more than four/day)
Suctioning/Pulmonary Toileting - excludes routine bulb suctioning less frequently than every two hours (based on current diagnosis and/or signs and symptoms within the past 3 months)	Oral/Nasal/Tracheal (as needed/up to two/week)	Oral/Nasal/Tracheal (Daily); Bulb syringe every two hours or more often than every two hours	Oral/Nasal/Tracheal/(up to three/day)	Oral/Nasal/Tracheal (more than three times each day)
Tracheotomy Care	X[2]	M[2]	Daily	Replace (Ties, Trach, or Dressing), Room air mist to trach
Percussion/Chest PT	As needed (One to two/week)	Daily/as needed (up to two/day)	Daily/as needed (Two to four/day)	Daily/as needed (more than four/day)
O2 sat/apnea monitor	X[2]	More than three false apnea episodes per day	Scheduled less than every 2 hours	Every two hours - Continuous
O2 administration/Ventilation/BiPap/		As needed	Scheduled/not	Continuous

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
CPap			continuous	
Cardiovascular				
Perfusion/Circulatory Assessment (based on current diagnosis and/or signs and symptoms within the past 12 months)	As needed (Adverse Heart/Lung Exchange), in addition to daily health assessment	M[2]	W[2]	D[2]
Heart Rate/BP (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2]	W[2]	D[2]
Cyanotic episodes (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2]	W[2]	D[2]
Frequent rest periods	X[2], or with activity	M[2]	W[2]	D[2]
Hydration Status (includes nutrition)	X[2]	M[2]	W[2]	D[2]
Fluid Balance (I/O) (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2], Occasional fluid overload	W[2], Weekly fluid overload	D[2], Daily fluid overload
Venipuncture/Port or Central Line Access	X[2]	M[2]	W[2]	D[2]
Endocrine				
Endocrine Regulatory Disorder – Exclude Diabetes Mellitus	X[2]	M[2]	W[2]	D[2]
Glucose Monitoring	As needed/Weekly (Blood or Ketones)	Daily/As needed (One to two/day) (Blood or Ketones)	Daily/As needed (Three to four /day) (Blood or Ketones)	Daily/As needed (More than four times daily) (Blood or Ketones)
Neurological				

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Level of Consciousness (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2], Alert w/ occasional decrease or cloudiness	W[2], Lethargic/Obtunded,	D[2], Stupor/Coma
Mental Status (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2], Limited Orientation	W[2], Confused	D[2], Confused/Safety Risk
ICP (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2], Risk for increase - no shunt	W[2], Risk for increase - shunt	D[2], Increased
Syncope (based on current diagnosis and/or signs and symptoms within the past 12 months)	X[2]	M[2], Near syncope - no falls	W[2], Near syncope- falls	D[2], Syncope episodes
Sensory Disorders (Sensory Integration/ Decreased Sensation/Pain Sensitivity)	X[2]	M[2]	W[2]	D[2]
Motor Tone & Strength (based on current diagnosis and/or signs and symptoms within the past 12 months)	Diagnosis or History of Hypotonia/Hypertonia	Weakness in one extremity	Weakness in 2 extremities, including Right or Left-sided weakness	Severe generalized weakness
Spasms/Involuntary Movements	Involuntary movements of one body part	Involuntary movements of multiple body parts and/or infantile spasms less than daily	Involuntary movements of multiple body parts and/or infantile spasms daily	Involuntary movements of multiple body parts and/or infantile spasms multiple times daily
Seizures (based on current diagnosis and/or signs and symptoms within the past 12 months or symptoms controlled with medical management during the past 12 months)	History/ No active seizures in past year	Seizures not with cardio-respiratory symptoms monthly or less	Seizures with cardio-respiratory s/s monthly or less/seizures weekly	Seizures with cardio-respiratory s/s weekly or greater or any seizures daily

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Risk for Falls/Environmental Safety/Seizure Precautions-Exclude age-appropriate risk and falls risk related to Syncope	X[2], or with activity	M[2]	W[2]	D[2]
Hearing/Vision – Based on signs and symptoms within the last 3 months; Care and maintenance of assistive devices is included in baseline points	X[2], No device pending hearing and/or vision test	M[2], Some impairment even with device	W[2], Partial Blindness or Deafness	D[2], Blind or Deaf
Gastrointestinal				
Reflux (based on current diagnosis and/or signs and symptoms within the past 3 months or symptoms controlled with medical management)	Risk for Reflux, more than daily assessment	Occasional signs and symptoms and/or intervention	Frequent signs and symptoms and/or intervention	Signs and symptoms at every feeding with intervention
Regime Intervention - Chronic Diarrhea/Constipation (based on current diagnosis and/or signs and symptoms within the past 3 months or symptoms controlled with medical management)	X[2]	Routine Invasive Bowel/Current Chronic Constipation	Chronic Diarrhea (other systems assessed)	Chronic Impaction/Invasive Bowel Maneuvers or Frequent Dehydration related to diarrhea
Feeding Tube Care – Includes feeding tube site care	X[2]	Daily intervention	Intervention two times daily	Intervention more than two times daily
Colostomy/Ileostomy	X[2]	Intervention more than one time month	Intervention more than one time week	Intervention more than one time daily
Feeding/Nutritional Needs				
Route			PO/Feeding Tube Combination	Feeding Tube Only
Frequency of Tube Feedings	Less than daily	Daily	More than daily	Every two hours to Continuous

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Difficulty Feeding r/t dysphagia, mechanically altered diets, thickened liquids, oral motor disorders, Upper Extremity mobility limitations, risk for aspiration, Activities of Daily Living adaptive equipment, therapeutic feeding techniques, activity intolerance	Supervision Only; X^2	Minimal Assist with supervision; 1:1 Supervision with meals; M^2	Moderate Assistance; more than 30 minutes each meal to feed infant up to 12 mos old; W^2	Total Assistance; more than 45 minutes each meal to feed infant up to 12 mos old; D^2
Appetite/Nutrition Status (based on current diagnosis and/or signs and symptoms within the past 12 months)	X^2, monthly weights	Overeats/Underweight/Needs encouragement, weekly weights	Mal/Under nourished, more than weekly weights	Food Diary and Frequent RD or Nutritionist Intervention
Therapeutic or Special Diet/Food Allergies - (diabetic, renal, healthy heart diet, etc.)	No more than monthly monitoring & intervention; X^2	No more than weekly monitoring & intervention; M^2	No more than daily monitoring & intervention; W^2	More than daily monitoring & intervention; D^2
Genitourinary				
Vesicostomy/Ureterostomy	X^2	Intervention more than one time month	Intervention more than one time weekly	Intervention more than one time daily
Catheterization	Once daily (independent with nurse oversight)	Once daily (needs assistance) or 2 times daily (independent with nurse oversight)	Two times daily (needs assistance) or more often (independent with nurse oversight)	Three times daily or more (needs assistance)
Chronic Infections (based on current diagnosis and/or signs and symptoms within the past 3 months or symptoms controlled with medical management)	X^2, History/Risk for	Chronic Skin Infections of genitourinary area with at least monthly intervention	Chronic urinary tract infections/Skin infections of genitourinary area with weekly intervention	Chronic urinary tract infections/Skin infections of genitourinary area with more than weekly intervention
Urinary Retention (based on current diagnosis and/or signs and symptoms within the past 3 months or symptoms controlled with medical management)	X^2	Signs and symptoms monthly or less with intervention	Signs and symptoms weekly or more with intervention	Daily signs and symptoms with intervention
Integumentary				

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Wound Care - Exclude topical treatments without other wound care orders; Exclude G-Tube or other feeding tube sites	One dressing daily/one wound	One dressing daily/more than one wound	Two to three dressings daily	More than three dressings daily
Eczema	Occasional exacerbations with treatments	Frequent exacerbations not affecting daily functioning	Severe-affects daily functioning	
Skin Protocol for Limited Mobility	No skin breakdown, assistance with pressure relief related to device or encourage mobility related to AFO or splint	No skin breakdown/assist to turn (pressure relief) every hour or less	No current skin breakdown/assistance with pressure relief more frequently than every hour	Current skin breakdown/ dependent for pressure relief more frequently than every hour
Musculoskeletal				
Equipment/Braces-Any Brace/ splint/ AFO/ DAFO/cast/cane/ walker/ gait-trainer/ wheelchair/ crutch/ prosthesis - Refer to definitions[3] for supervision, and minimal, moderate, and total assistance	Supervision Only with set up	Minimal Assistance with set up	Moderate Assistance with set up	Total assistance with set up
Limited Range of Motion/Poor Muscle tone - Exercise/massage; Follow-thru Therapy to carry out therapeutic plans and interventions	One extremity	Two extremities	Three extremities	Four extremities
Therapy				
Therapy Services (ST, OT, PT, DI, CLS, RT, etc.) - Follow-thru Therapy to carry out therapeutic plans and interventions	Monthly with follow thru therapy	Biweekly with follow thru therapy	Weekly with follow thru therapy	More than once weekly with follow thru therapy
Registered Dietician/Nutritionist - Follow-thru Therapy to carry out therapeutic plans and interventions	Monthly with follow thru therapy	Biweekly with follow thru therapy	Weekly with follow thru therapy	More than one time each week with follow thru therapy
Level of Self Help/ADLs				

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Transfers/Eating/Toileting/Mobility - More than 3 years old; Refer to definitions[3] for supervision, and minimal, moderate, and total assistance	Supervision Only	Minimal Assistance with supervision	Moderate Assistance with supervision	Total Assistance
Bowel and Bladder Incontinence	Urinary Incontinence/ more than three years old; intermittent urinary incontinence less than daily/more than three years old	Bowel Incontinence/ more than three years old; Urinary incontinence more than six years old; intermittent urinary incontinence daily/more than three years old	Bowel Incontinence/ more than six years old; intermittent urinary incontinence more than daily/more than three years old	
Developmental				
Cognitive/Communication/Social & Emotional/Fine Motor& Gross Motor/Adaptive – Refer to Developmental Delay Definitions[4]	**Mild delay one** major area	**Mild delay two** major areas; **Moderate delay one** major areas	**Moderate delay two** major areas; **Severe delay in at least one** major areas	**Severe delay in at least 2** major areas
Interaction with Peers/Staff/Emotional Affect	Routine behavior modification program including redirection, bargaining, structured diversion & reinforcement	Individualized Behavior Modification program	Evaluation & Revision of Behavior Modification program to promote effectiveness	Continuous staff assessment and intervention
Case Management - Coordinating and referring services through family and/or provider and community resource meetings, phone calls and other provider or community resource communications	More than one intervention every six months	Monthly intervention	Weekly intervention	Daily intervention
Medication Administration				

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)				
Scheduled/Reconciliation/Compliance/Route/Frequency (PO,GT,PR,Topical/Sub-Q/IM/IV/IVP)	Routine/as needed meds weekly/daily/Assessing medication effectiveness of facility and non-facility administered medications	Two times daily any route; at least three meds administered per one route at the same scheduled time at least one time daily	Three times daily any route; at least three meds administered per multiple routes at the same scheduled time at least one time daily	More than three times daily any route or IM, IV, IVP
Insulin	As needed	Once per day	Two times daily	More than two times daily
Controlled Substances	As needed	Daily	Two times daily	More than two times daily
Emergency/Rescue medications - Inhalers, Epipen, Diastat, etc.	Less than monthly	At least monthly	At least weekly	At least daily
Environmental				
Risk for Infection - based on current diagnosis and/or signs and symptoms within the past 3 months or symptoms controlled with medical management	X[2]	M[2]	W[2], Risk for Immunosuppression	D[2], Immunosuppression
Total Points Each Row:				
Sum of Total Points per Column - Acuity Points Total:				
Comments:				

Prescribed Pediatric Extended Care Prior Authorization Leveling Evaluation Tool (Revision August 23, 2011)
Refer to Prescribed Pediatric Extended Care (PPEC) Leveling Evaluation Tool (LET) Summary for: • **Standards for Baseline Acuity for PPEC Services** • **Scoring Table**
[1]**12 Standard Points for Baseline Acuity for PPEC Services:**
Daily Health Assessment (1 point) **Additional Daily Health Assessment in one system as ordered by physician (1 point)** **Case Management (1 point)** **Precautions and Interventions for conditions with active signs and symptoms or diagnosed and treated events within 12 months of service:** **• Skin Care including lotions, sunscreens of choice and treatments for superficial skin disruptions (1 point)** **• Safety Precautions (1 point)** **• Problem oriented health assessment in one system as needed, including but not limited to interventions to address seasonal, environmental and medication allergies (1 point)** **• Infection Precautions including monitoring and reporting signs and symptoms of infection and administering and monitoring effectiveness of and adverse reactions to medications ordered to treat infections (1 point)** **• Choking and Aspiration Precautions including sitting up for 30 minutes after meals and procedures, supplies and staff training to respond to choking and aspiration (1 point)** **• Individualized, structured play (1 point)** **• Assistance with personal adaptive equipment, devices and belongings, including but not limited to vision & hearing devices, splints, AFOs, and positioning support devices (1 point)** **• Monitoring meal & fluid intake (1 point)** **• Parent/Family/Primary Caregiver Education (1 point)**
[2] **Frequency of Assessment-X** –At least one additional assessment with intervention in past 3 months; **M** – At least one additional monthly assessment with intervention; **W**– At least one additional weekly assessment with intervention **D** – At least one additional daily assessment with intervention
[3] **Assistance Definitions: Supervision**-Oversight, encouragement or cueing provided-**Minimal**-Child highly involved in activity, received physical help with guided maneuvering of limbs or other nonweight-bearing assistance -**Moderate**-Child performed part of activity with the following help provided: weight-bearing support or full staff performance-**Total**-Full staff performance of activity
[4] **Developmental Delay Definitions: Mild**-Less than 3 months delay -**Moderate**-3 to 6 months delay-**Severe**-More than 6 months delay

Table 1. Chronic Conditions of children with medical complexities (CMC)

Cancer	Neurological Pathologies
Cerebral Palsy	Orthopedic conditions
Chronic Lung diseases	Oxygen Dependence
Congenital Anatomical malformations	Prematurity & complications
Congenital Cardiac anomalies	Perinatal conditions
Cystic Fibrosis	Post-acute Burn treatment
Eating or Metabolic disorders	Respiratory disorders
Enteral Feeding	Sickle Cell disease
Genetic diseases	Short Bowel syndrome
Head Trauma	Spina Bifida
Hemodialysis	Traumatic Brain Injury
HIV/AIDS	Ventilation Assistance

Table 2. Family Impact Module (FIM) Dimensions

Dimension	Pre-PPEC	Post-PPEC
Physical Functioning	PFS1	PFS2
Emotional Functioning	EFS1	EFS2
Social Functioning	SFS1	SFS2
Cognitive Functioning	CFS1	CFS2
Parent Health-Related Quality of Life	PHRQOL1	PHRQOL2
Communication	CS1	CS2
Worry	WS1	WS2
Daily Activities	DAS1	DAS2
Family Relationships	FRS1	FRS2
Family Functioning	FFS1	FFS2
Family Impact (FIM) Total	TSS1	TSS2

Table 3. Descriptive Statistics of survey respondents (N=24)

Characteristic (Dimension)	n= (%)	Family Impact (FIM total) Mean (SD)		Parent (HRQOL) (PHRQOL) Mean (SD)		Family Functioning (FFS total) Mean (SD)		Communication (CS) Mean (SD		Worry (WS) Mean (SD)	
		Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Center											
01	8 (33.3)	54.98	69.99	57.20	68.52	49.58	74.58	59.37	72.92	52.5	63.75
02	3 (12.5)	56.34	73.11	61.56	74.41	60.0	79.72	52.78	61.11	31.67	66.67
03	1 (4.2)	62.23	98.85	65.21	97.71	55.83	100.0	58.3	100	75.0	100
04	5 (20.8)	60.49	77.4	60.65	74.96	59.0	81.67	58.33	70.0	65.0	86.0
05	4 (16.7)	43.11	68.49	45.08	72.92	32.29	68.13	62.5	62.5	37.5	57.5
06	3 (12.5)	58.06	71.67	61.81	68.19	46.39	72.5	61.11	72.22	63.33	83.33
CMC Gender											
Male	18 (75)	52.34	73.65	54.14	73.79	46.8	75.93	57.41	72.22	51.11	70.0
Female	6 (25)	63.18	71.37	66.98	68.65	58.89	77.92	63.89	63.89	55.83	76.67
CMC Acuity											
1	-	-	-	-	-	-	-	-	-	-	-
2	14 (58.3)	57.04	72.88	59.76	72.57	52.38	76.66	58.92	67.26	53.57	72.14
3	7 (29.2)	50.36	74.02	50.59	74.04	46.31	78.33	57.14	71.42	50.71	67.86
4	3 (12.5)	56.7	71.86	61.87	68.57	46.11	70.83	63.88	80.55	50.0	
Guardian Caregiver											
Mother	18 (75)	53.576	75.46	54.23	75.16	48.28	77.91	57.86	73.61	57.22	73.61
Father	3 (12.5)	54.02	55.64	61.81	53.64	45.55	61.67	63.88	55.55	30.0	51.67
Grandparent	2 (8.3)	68.07	82.78	73.43	82.44	67.08	89.58	66.67	70.83	50.0	82.5
Other	1 (4.2)	58.54	63.13	67.92	61.25	55.83	67.5	50.0	50.0	35.0	75.0

Table 4. Dependent Samples T-Tests Results

Dimension	Mean Admission Score	Mean Post PPEC Score	Mean Difference	Std. Deviation	t-value	Degrees of Freedom	Significance 2-sided p
Family Impact (FIM total)	**55.05**	**73.08**	**18.04**	**19.16**	**-4.612**	**23**	**<.001**
Parent Health Related Quality of Life	57.35	72.50	15.15	23.13	-3.21	23	.004
Family Functioning (FFS)	49.83	76.42	26.60	16.89	-7.72	23	<.001
Communication (CS)	59.03	70.14	11.11	28.94	-1.88	23	.073
Worry (WS)	52.29	71.67	19.38	24.60	-3.90	23	<.001

Table 5. PPEC standards of care

Alabama	Chapter 58A-13. Prescribed Pediatric Extended Care Centers (PPEC) https://ahca.myflorida.com/Medicaid/childhealthservices/ppec/index.shtml
Delaware	Administrative Code: Title 16. Department of Health and Social Services. Division of Public Health. 4400 Health Systems Protection (HSP). 4409 Prescribed Pediatric Extended Care Centers (PPECC). https://regulations.delaware.gov/AdminCode/title16/Department
Florida	Chapter 58A-13. Prescribed Pediatric Extended Care Centers (PPEC). https://ahca.myflorida.com/Medicaid/childhealthservices/ppec/index.shtml
Georgia	Chapter 58A-13. Prescribed Pediatric Extended Care Centers (PPEC). https://ahca.myflorida.com/Medicaid/childhealthservices/ppec/index.shtml https://dch.georgia.gov/divisionsoffices/healthcare-facility-regulation/hfr-laws-regulations
Kentucky	902 KAR 20:280. Prescribed pediatric extended care centers. https://apps.legislature.ky.gov/law/kar/902/020/280.pdf
Louisiana	Louisiana Department of Health and Hospitals, Health Standards Section - Chapter 52. Pediatric Day Health Care Facilities. https://ldh.la.gov/assets/medicaid/hss/docs/PDHC/Pediatric_Day_Health_Care_Regs.pdf
Minnesota	Minnesota Statutes Chapter 144H.01-.20 Prescribed Pediatric Extended Care Centers. https://www.health.state.mn.us/facilities/regulation/ppec/index.html
Mississippi	Mississippi State Department of Health Title 15. Health Facilities Part 16. Health Facilities Licensure and Certification SubPart1. Minimum Standards of Operation of Prescribed Pediatric Extended Care (PPEC) Centers Chapter 2. https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/prescribed-pediatric-extended-care-centers/how-become-a-ppecc-provider Health and Safety Code Title 4. Health Facilities Subtitle B. Licensing of Health Facilities Chapter 248A – Prescribed Pediatric Extended Care Center. https://statutes.capitol.texas.gov/Docs/HS/htm/HS.248A.htm
Pennsylvania	Department of Health. Division of Home Health. Title 35 P.S. Health and Safety, Ch. 1H -Prescribed Pediatric Extended Care Centers Act -449.61-449.77 (Nov. 24, 1999), P.L. 884, No. 54, Sections 1-18. https://www.health.pa.gov/topics/facilities/Pages/Pediatric.aspx
Tennessee	Bureau of Health Licensure and Regulation. Rules of Tennessee Department of Health Board for Licensing Health Care Facilities. Division of Health Care Facilities. Chapter 1200-08-02.01-.14 Standards for Prescribed Child Care Centers. https://sharetngov.tnsosfiles.com/sos/rules/1200/1200-08/1200-08.htm
Texas	Texas Administrative Code. Title 26 Health and Human Services. Part 1 Health and Human Services Commission. Chapter 550.1-.1409 Licensing standards for Prescribed Pediatric Extended Care Centers. https://hhs.texas.gov/doing-business-hhs/provider-portals/long-term-care-providers/prescribed-pediatric-extended-care-centers-ppecc PPECC@hhsc.state.us.tx. or for licensure ppecc@dads.state.tx.us.
Virginia	HB 1719 passed the House 2/11/20 and the Senate 2/25/20. https://lis.virginia.gov/cgi-bin/legp604.exe?201+sum+HB1719