Family Engagement in Pediatric Medical Home serving Children with Medical Complexity (CMC)

Santa, S[1,2], Woods, AC[1,2], Sharp, K[2], Berhane, R[2,4], Goldstein, I [3], Alexander MA[2], Rosenbloom AH[2,4], Kirsch, L[4]

1) Texas Parent to Parent, Austin, Texas; 2) Dell Children's Medical Center of Central Texas, Austin, Texas Children's Comprehensive Care Clinic; 3) Texas Department of Health and Human Services, Maternal Child Health Bureau; 4) Dell Medical School at The University of Texas at Austin

Background

Active, meaningful engagement of families provides a valuable model for achieving the best care for children with medical complexity (CMC). Complex care is provided by many dedicated clinics, yet not all clinics have parent advisory groups or meaningful focus on family engagement.

Pediatric care and coordination of services for children with medical complexity (CMC) is fragmented and costly. Children's Comprehensive Care Clinic (CCC) serves CMC that account for ~ 1-3% of the pediatric population and 30% of health care cost. The children have at least 3 chronic and life limiting diseases, may use technology, and see multiple specialists. The children's complexity may drive high utilization and requires the parents to carry the load of alerting providers to changes in their child's needs and services. Current metrics for successful delivery of appropriate care and services for CMC are mainly evaluated through reducing: emergency department visits, length of hospital stays, use of specialists, etc. Yet, these measures miss identifying individual goals and what matters most to CMC and families.

CCC's family focused healthcare innovations have current support through HRSA's **Collaborative Improvement and Innovation Networks (CoIIN) to Advance Care for CMC** and improve the well-being of CMC and their families.

Methods

CCC established a *'family workgroup'* comprised of CMC parents (of children inside and outside of CCC) with the intent of ensuring meaningful family engagement and sharing of diverse perspectives. This *family workgroup*, is led by Texas Parent to Parent (TXP2P): Family – Family Health Information Coordinator. The *family workgroup* worked with national partners to develop/ finalize family surveys for use in the 10 states participating in CoIIN.

Methods (Continued)

The survey focused on several outcomes with three key measures specific to family engagement in CCC:

a) Continued ***engagement of CCC parents*** in CCC & the CMC CoIIN Family Workgroup
b) Utilization of survey results to assess trends and identify *areas for clinic process improvement* and practice changes [***'family well-being', 'family engagement', and 'child quality of life'***]
c) Identify the percentage of CCC parents reporting ***'knowledge' and presence of a plan of care (POC)*** for their child**.**

TXP2P received funding from CoIIN and Texas Title V/ CSHCN for family stipends for participating in monthly Workgroup and survey administration every 6 months. CoIIN funded gift cards to the parent respondents of the survey. Once parent consents for surveys were provided, parent first name and contact phone number were forwarded to surveyors. No identifying data was shared and parents were asked not to reveal their children's identity to the phone surveyor. Data collected from survey responses were handled confidentially and recorded anonymously. Each time frame, ~ 90 clinic families were asked to participate in surveys and resulted in '37' (Time 1) and '40' (Time 2) respondents.

Discussion

Baseline survey data was attained across '2' randomized parent groups (including '9' Spanish speaking parents) in 9 months. Parent responses provided areas to focus changes in clinical processes to improve the children's and parent's perceptions of their child's care. Families need to be involved at all levels of leadership pertaining to the care of their child.

Results

Table 1: Ethnicity and Language

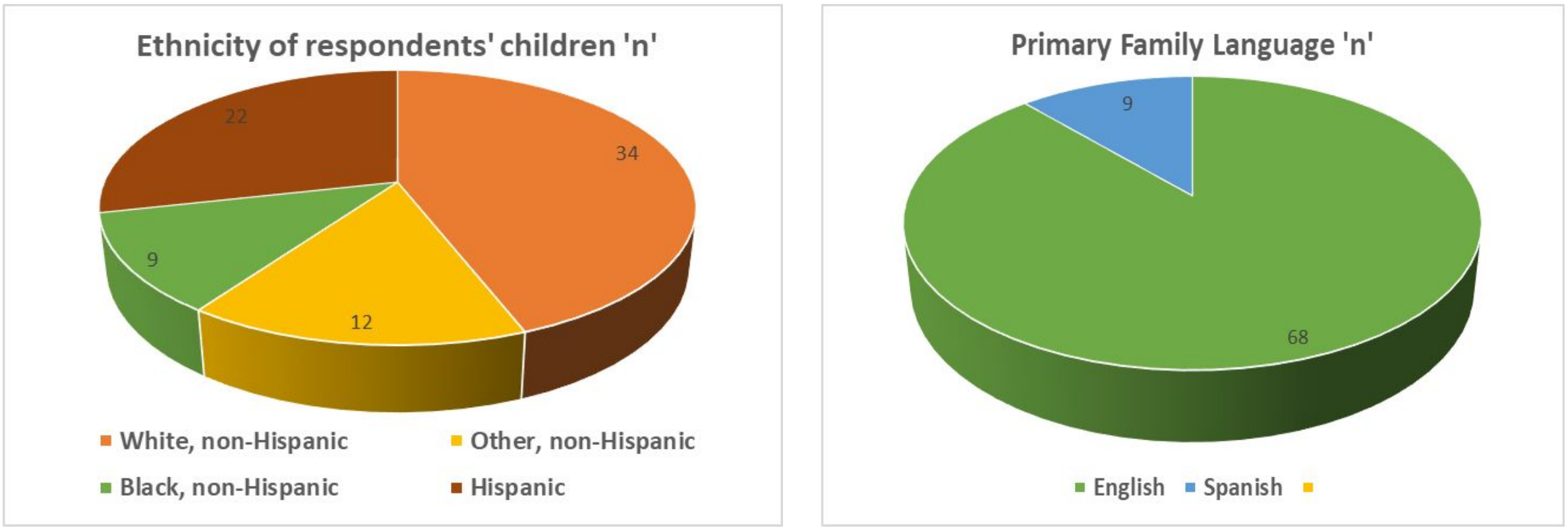


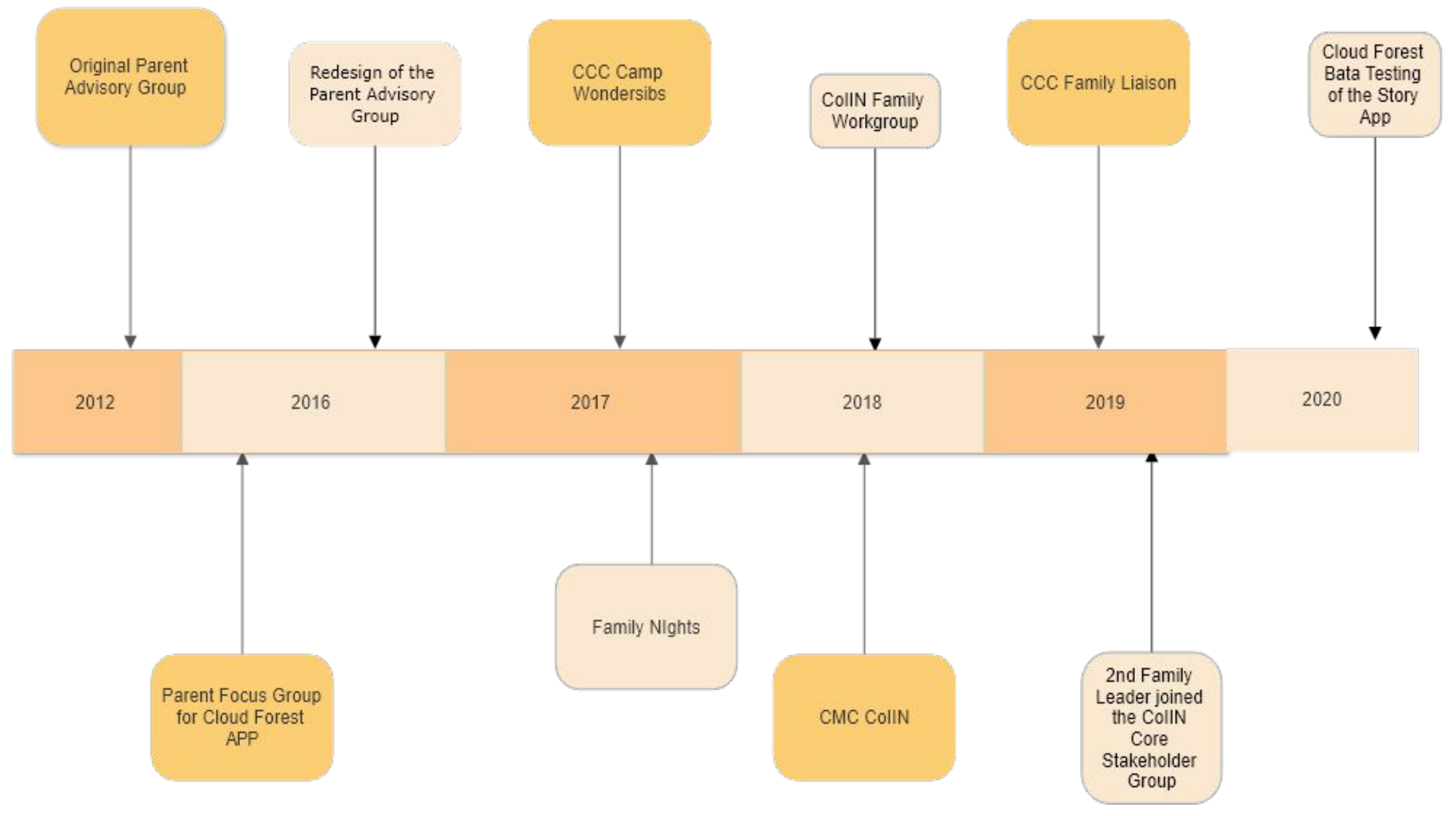
Table 2: Survey results

Survey Results *Composite Scores on '4' domains*	% responding favorably [to domain questions]				
Shared Plan of Care	46.0				
Child Quality of Life (plans for the future and a meaningful life)	80.3				
Family Engagement	79.4				
Family Well Being [care team/provider asks about caregiver emotional stresses]	55.0				
Family Well Being (***'n' of responses to** unique questions*)	**Mean** (hrs/wk)	**Median**	**Standard Deviation**		
care coordination **and** 'hands-on' care for CMC	61.8	39	63.7		
care coordination only for CMC	16.7	5	31.4		
'hands-on care' of child only for CMC	106.5	100	55.4		
In the past 12 months:	**Never**	**Sometimes**	**Usually**	**Always**	**answer**
Provider discuss'd range of options to consider for child's treatment?	0	11	16	43	7
Provider made it easy for you to raise concerns/ disagree with recommendations for child's care?	1	4	9	56	7
Provider worked with you to decide, together, treatment choices best for your child?	1	5	10	52	9

Discussion (cont'd)

The surveys developed and approved by CoIIN workgroups (staff and families) continue to be a way to track more meaningful metrics and quality improvement changes. CoIIN reinforced the best practice of having a 'parent' in the family liaison role. In 2019 CCC hired a parent of children with disabilities and other health care needs into this position.

Table 3: Parent/ Family Engagement activities



Conclusion

The CCC family liaison guiding the family workgroup and parent/family advisory council will inform the healthcare team of meaningful ways to drive clinical change at CCC. This is the proposed roadmap to address the multiple components of 'family wellbeing.'