RE: Comments on Medi-Cal 2020 Demonstration CCS Draft Evaluation Design

Dear Director Kent;

Our undersigned organizations are writing to comment on the Department of Health Care Services’ (DHCS) draft evaluation design for the California Children’s Services (CCS) Program submitted to the federal Centers for Medicare and Medicaid Services (CMS).

Overall we support the direction and tone of the draft evaluation design for the two CCS pilots: Health Plan of San Mateo (HPSM)/San Mateo County and the ACO intended for implementation by Rady Children’s Hospital - San Diego. We believe the Department has made a good start in identifying critical components of an evaluation strategy for these pilots. We also believe that many of the components described in the draft would be useful to include in the evaluation plan for implementation of the Whole Child Model (WCM) in 21 COHS counties, as mandated by SB 586 (Chapter 625, Statutes of 2016).

One general recommendation we would make is for the Department to clarify that the metrics it will use to evaluate each pilot will be specific to the population of CCS children enrolled in the pilot. For example, the ACO pilot will only cover children with five CCS conditions: acute lymphoblastic lymphoma (ALL); hemophilia; diabetes in children under the age of ten; sickle cell anemia; and cystic fibrosis. Therefore, the metrics used to evaluate it should only include children and youth in San Diego County with one of those five CCS conditions.

We have also provided some additional comments on specific areas of the evaluation plan below.

Goals and Objectives (Pages 1-2)

Overall, we strongly support the goals and objectives laid out in the draft. We are particularly pleased to see that the Department intends to measure family/patient and provider satisfaction with the delivery of services, as well as to assess impact on health outcomes. However, we would like to see Objective #5 amended to read, “Increasing the use of ‘out-patient care’ as an alternative to inpatient care and emergency room use,” as opposed to ‘community-based services’, given that many communities do not have large enough CCS populations to support the full range of community-based CCS-approved services and providers.

With regard to Objective #4, we also request clarification of the intent as it is unclear whether the objective is to evaluate the state’s ability to measure and assess strategies that are most and least effective in care delivery or if the objective is to actually measure and assess which strategies are most and least effective in care delivery based on outcomes. We assume that the Department intended the latter and can clarify this in the next iteration of the plan.
**Evaluation Design and Methods (Page 2)**

We strongly support the Department’s plan to compare pre- and post-pilot implementation data “whenever possible”, and specifically support the commitment to using 24 months of pre-implementation data. We are concerned that, to our knowledge, there are not comprehensive baseline data for the HPSM pilot, which has been formally implemented for more than three years, despite the Department’s public commitment to evaluation of that pilot prior to its launch. If there are comprehensive baseline data, we request that the Department publicly release what data are available and how they were collected. We reiterate the importance of establishing baseline data as part of this evaluation, as DHCS should be able to assess current (baseline) patterns of CCS enrollment and utilization. We would also like to see the baseline and post-intervention data be made available to allow other evaluators or even “crowd-sourced” evaluations to be done to validate the findings of the sponsored evaluation.

We support the concept of comparing pilot performance in the two counties to “selected counties where CCS services are not incorporated into managed care or an ACO”. However, we caution that it may be extremely difficult to find appropriate county matches for both San Mateo and the Rady ACO. Many stakeholders—including HPSM staff—have noted that San Mateo County is unusual, given its geographic location and close proximity to and historical relationships with two major quaternary children’s hospitals. In addition, San Mateo has a relatively small number of pilot enrollees and the Rady ACO will enroll an even smaller number of children. Nevertheless, we expect the Department to give careful and thoughtful consideration of comparison counties based on CCS population size and demographics, the Medi-Cal managed care delivery landscape, and CCS-paneled provider networks and types.

**Evaluation Measures (Page 3)**

With regard to Measure 1 (Percent of new enrollment) and Measure 2 (average length of enrollment), we note that the baseline value is “TBD”. The Department should tell stakeholders how they will compute this value and provide the data. In addition, we would like to see that all evaluation measures are appropriately risk adjusted, and that minimum denominators are established for each measure, as some subpopulations may be too small to draw accurate conclusions from.

**Access to Care (Pages 3-5)**

Measure 1 (Percent of children and young adults 12 months–20 years of age who had a visit with a PCP): We note that, while it is an important, and standard, HEDIS measure, this indicator will not contribute to assessing the CCS pilots’ impact specifically on children with CCS-eligible conditions.

Measure 2 (Referral of a Child to Special Care Center (SCC)): We support inclusion of this measure, but also strongly recommend that the Department include an additional measure, which would capture the percentage of children/youth with SCC-eligible conditions who actually receive at least one annual visit to a SCC, and the average length of time they have to wait between their doctor making the referral and the visit itself. Referral to and authorization of treatment by SCCs is extremely important for children/youth with SCC-eligible conditions, as the SCC multi-disciplinary team approach is a cornerstone of CCS care for children with particular complex medical conditions. At the same time, we think it is critical that we ascertain that these children actually reach the SCC for at least an annual visit, as there are elements of these pilots that could either promote or hinder such access, and it is important to identify a trend in either direction should one develop.
Measure 3 (Screening for Clinical Depression and Follow-Up Plan): We think this is an important measure for all children and youth and we applaud the Department for including it as part of the External Accountability Set. However, we are not familiar with the exact technical specifications of this measure and would like to know what age-appropriate standardized depression screening tool the Department is planning to require and when it will be implemented statewide (implementation will have to be required statewide in order for there to be cross-county comparisons). It is also unclear how often the Department intends these screenings to be done. The language used to describe the metric refers to “the date of the encounter”. Many CCS children have multiple visits with their primary care physician and various specialists in a given year. Will all providers in these two pilots be expected to administer a depression screening at each appointment? This seems like it would impose a significant burden on providers, and it’s not clear how much of a benefit multiple, annual screenings would provide. As we noted with regard to the PCP visit in Measure 1, data from this measure will not contribute to an assessment of access to care directly related to CCS conditions. For this reason, we stress that the two SCC-related measures discussed under Measure 2 above are both important for assessing pilot impact on sub-specialty access.

In addition, we note that the Department’s hypothesis is that the CCS pilots will ensure access to “timely and appropriate, high-quality and well-coordinated care….“ but none of the measures proposed here look at the timeliness of care delivery in the pilots. We recommend the department measure appointment wait time. California is perhaps the most advanced state in terms of developing and monitoring metrics for timely access to care in a managed care environment. The department should draw on existing resources in the state—it’s own staff in the Managed Care Quality & Monitoring division along with staff at the Department of Managed Health Care—to adapt those measures and monitoring techniques for these two pilot projects.

Since the Department will be developing time and distance standards for pediatric specialists as required by the new federal Medicaid Managed Care Rule, we recommend that the evaluation plan add a measure that shows how well the pilot programs are meeting these time/distance standards once they have been developed.

**Client Satisfaction (Pages 5-6)**

Measure 1 (Surveys of families related to satisfaction with participation CCS Pilot including both primary care and subspecialty care access and quality of services): As we noted earlier, we are pleased that the evaluation design includes family satisfaction. We observed that for the HPSM pilot the evaluation will be cross-county comparison and wonder whether there are sufficient CAHPS survey data (by plans and of CCS enrollees) available from pre-pilot implementation that could be used for pre-post comparisons. In addition, we encourage the Department to consider how they might use the Title V Needs Assessment family survey data as pre-pilot data by employing the Title V family survey as a post-implementation survey tool. The Department might also consider adding a quality-of-life measure like the Pediatric Quality of Life Inventory TM or the Child Health Ratings Inventory.

Measure 2 (grievances and appeals): We typically regard looking at the number of grievances and appeals as not very reflective of satisfaction, since family organizations routinely report that families decline to pursue them, given the amount of time and effort required. Nevertheless, we agree that these data should be included in the evaluation. We are puzzled that the evaluation plan assumes that there is no comparison group because data are not comparable pre-pilot or across counties. We understand that the ACO situation will be more complicated, since it will include a small subset of the county’s CCS enrollees, but we do not understand why grievances
and appeals in the HPSM pilot cannot be compared to the pre-pilot number and types in San Mateo.

**Provider Satisfaction (Page 6)**

We support the intent to survey a broad array of physicians, hospitals, clinics pharmacy and Durable Medical Equipment (DME) providers regarding their satisfaction. Given the increasing problems we have noticed with access to medications and DME because of problems with reimbursement, we are particularly pleased that reimbursement will be looked at as a factor in satisfaction. Is the Department considering using the Title V Needs Assessment provider survey as a tool and pre-pilot sample? If not, has the Department identified a survey tool? We would be very willing to assist in developing the survey if one has not yet been selected.

**Quality of Care (Pages 6-7)**

Measure 1 (Childhood Immunization Status): As noted with several other items above, this is a standard HEDIS measure and, while important for children’s health status, this measure will not provide information regarding changes in quality of care specific to children’s CCS conditions. There are some CCS diagnoses that are contraindicated with vaccines. The denominator for this measure should be adjusted accordingly.

Measures 2 and 3 (Subspecialty care for Diabetes - HbA1c Testing; and Lung Function for Cystic Fibrosis patients): We believe the diabetes measure and national benchmark are appropriate. However we do have several concerns. As mentioned earlier, the denominators for these conditions will often be very small and may render the measures not statistically valid, which, given the size of the HPSM pilot enrollment and the likely enrollment in the Rady ACO, will be a significant limitation. We also seek clarification as to whether these measures will be calculated using a denominator that only includes children with multiple CCS conditions AND a specific diagnosis of cystic fibrosis or diabetes, which is how the denominator language for both the diabetes and cystic fibrosis measures currently reads.

We also have numerous concerns with the measure currently proposed for cystic fibrosis. The metric proposed from the Cystic Fibrosis Foundation (CFF) is a population measure and may not be appropriate for use in these evaluations. According to the Cystic Fibrosis Foundation Patient Registry (CFFPR) methodology, if a child has more than one FEV1 measurement recorded during a given year, the highest measurement in each quarter is chosen. Those values are then averaged to calculate the average FEV1 value for the individual patient. The benchmark is then risk adjusted by the CFF. In addition, the CFF uses several different FEV1 measures, stratified by age, which have different measurement and reporting periods. It’s not clear which one the Department is proposing to use here.

In addition to finding a more appropriate measure for CF, we strongly urge the Department to include outcome measures for each of the five conditions in the ACO Pilot, in its evaluation of both pilots. We also recommend the Department develop these five measures in collaboration with both pilot participants to make sure they are workable.

Finally, the Department should also consider adding a measure of caregiver burden (e.g., missed school days, missed work days).
Care Coordination (Pages 8-9)

Measure 1 (Family Experiences with Care Coordination (FECC) Survey): We are pleased that the draft evaluation plan proposes the use of the FECC survey, a nationally recognized and validated tool for measuring care coordination with children with medical complexity.

Measure 2 (Utilization of ER, IP, OP, Pharmacy and Mild/Moderate Mental Health Services for CCS children): In general we support collection and analysis of these data points, although we would like to see more detail regarding how the standards will be applied specifically to children with CCS-eligible medical conditions.

- With regard to looking at emergency room (ER) visits with an inpatient (IP) admission, we recommend that the Department look at ER visits without an IP admission, since they may be a better indicator of poor care coordination. (That is, an ER visit without an admission suggests that the medical issue could have been resolved outside the ER.)
- We are unclear what the Department would be measuring in capturing the rate of mild-to-moderate mental health visits, particularly since in many counties young children aged 0-5 are more likely to receive their mental health services through EPSDT county specialty mental health than through Medi-Cal managed care plans. In fact, in many counties older children and youth may be viewed as eligible for county specialty mental health services because of the impact of their CCS medical conditions. In these cases, CCS-enrolled children may not appear as receiving many visits via the mild-to-moderate mental health route, but nevertheless have significant mental health needs. The Department should provide more detail about what it hopes and expects to measure via this data point.

Total Cost of Care (Page 10)

We support the plan’s proposal to assess the total cost of care for children with CCS-eligible conditions. We agree that different payment mechanisms under the pilots could make the comparisons more complex and require the provision of claims data to complete the picture. We would like to remind the Department that a reduction in growth rate of expenditures for CCS children, either pre-post or in cross-county comparison, has to be weighed with consideration of all other evaluation measures, including access, satisfaction and quality, since expenditure growth may be contained at the peril of one or more of those more critical measures. In addition, it is possible that the CCS population in one of these pilots could become more medically complex as new children become eligible for the program, so any comparison between time periods should account for changes in patient complexity and other factors that drive health services utilization.
In closing, we are strongly supportive of many components of the evaluation plan, as noted above, and we congratulate the Department on their inclusion. At the same time, we would like to see the Department’s response to our recommendations for and questions about the draft plan, as we think our recommendations would strengthen the pilot evaluation.

We believe future iterations of this draft should form the basis of the evaluation plan for the implementation of the Whole Child Model, as mandated by SB 586, particularly with inclusion of our recommendations. To that end, and in recognition of the difficulties in evaluating the San Mateo pilot without sufficient baseline data, we strongly recommend that the Department begin the collection of relevant baseline data immediately, particularly those data that cannot be obtained retroactively through the Medi-Cal claims database or similar methods. This collection should be implemented not only in the 21 counties that will be implementing WCM, but also in the rest of the state, in order to facilitate evaluation of the functioning of the CCS program.

We thank you for the opportunity to review this draft; we look forward to your response.

Sincerely,