



Recommendations and Considerations

This section summarizes recommendations and considerations shared by the array of experts consulted for this report. While experts had a number of specific recommendations, particularly in the area of medical homes for CYSHCN, a key overall recommendation repeatedly heard was the need for the Lucile Packard Foundation for Children’s Health to plan and conduct its initiative in a coordinated manner that can benefit the entire state. Experts recognized the challenge of California’s size and diverse population, but felt strongly that even if an initiative were originally a pilot in a county or at the regional level, it had to be part of a coordinated effort to improve care across the state. Experts noted that at the federal grant level, California has been somewhat disadvantaged in discretionary grant funding because it receives the same amount of dollars as smaller states—enough to perhaps focus on one county, but not to effect statewide change. A larger and more population-appropriate statewide investment in some target areas could make a real difference.

In addition, experts emphasized the importance of strong and coordinated partnerships with Title V, pediatricians, family physicians, and family organizations to help plan and grow programs, and help provide the political capital to sustain promising programs.

The following provides some specific recommendations and considerations for the Foundation based on each topic covered.

SYSTEMS OF CARE

- Start with a focus on one issue (e.g., transition or health information technology) that is agreed upon by key stakeholders. As a next step, bring teams of state experts from model states/programs to California to participate in an action learning laboratory to provide a give and take between California leaders and other states.
- Consider the unmet mental health needs of the children as a whole and CYSCHN, in particular, when designing new initiatives.

MEDICAL HOME

- Invest funds in practice transformation by building the teams and the competencies necessary to provide appropriate medical homes. Ideally, this could be in partnership with Medicaid to provide funds for enhanced reimbursement.
- Provide funding to build and strengthen the capacity of state AAP chapters to promote medical home as practice. Some level of financial support, however modest, is important to pediatricians and other health care providers.

- Support the establishment of medical home efforts in primary care practices, not specialty care clinics. CYSHCN programs must build linkages to primary care, beyond specialty care. Look at providing incentives for sizeable networks that include primary care and medical homes in the network and provide an opportunity to model and evaluate programs.
- Medical home initiatives must connect with the larger community and system of services and not focus only on individual medical practices.
- When designing the evaluation of medical homes, it is important to look at evaluating costs in terms of savings in emergency room visits, savings in ratio of primary care/specialty care, and clinical outcomes such as reduced hospitalization. In addition, examine functional outcomes, such as school absences, family levels of satisfaction, work absences, and family stress.

CARE COORDINATION

- Invest in models that most meet the needs of families in California, whether practice, agency or home-based.
- Explore support for a central database or health record that contains all pertinent medical information as well as care coordination services as part of an overall quality improvement effort.
- Support a program or pilot that uses parent peers or care coordinators who are culturally and linguistically competent for the population being served in a particular practice or county.
- Support initial financial support for practices to have care coordinators on staff if a practice-based model is pursued.

FAMILY-CENTERED CARE

- Include family leaders in the planning and implementation process for Foundation activities for CYSHCN and include family involvement as a requirement for Foundation funding.
- Invest in family leaders at all levels, including executive level positions.
- Ensure that efforts invest in building family relationships. True family involvement requires time spent on key relationships, a financial com-

mitment and a level of support for family leader's growth.

- Continue to share with colleagues the value of family involvement, which is especially important in tough budget times. Family involvement is synonymous with consumer input which is a critical need as programs for CYSHCN across the country work to retain their operating budgets.

CULTURAL COMPETENCY

- Explore the use of cultural brokers to strengthen ties to targeted groups.
- Ensure that all Foundation efforts for CYSHCN include elements that provide for culturally competent care.
- Conduct or support focus groups with target populations throughout the state in order to provide more family-specific and culturally relevant information about the system of care of CYSHCN in the state.

TRANSITION

- Increasing public-private partnerships to make transition not only effective in terms of outcomes, but cost-effective as well.
- Focus on access to health insurance for CYSHCN, including helping youth maintain the insurance that they already have and increasing the maximum age at which CYSHCN can remain on their parental insurance to 25 years or higher. These efforts can help support sustainability of transition programs.
- Recognize that transition programs may cost money on the front end, but will generate money on the back end as CYSHCN are better transitioned to the work environment and thus able to become tax payers. Additionally, if a youth can live more independently, their caregivers may be able to return to work thereby generating more tax revenue.

RESPIRE AND PALLIATIVE CARE

- Invest in a strong infrastructure to support respite care services that takes into account diverse needs within the communities served, and focuses on

improvements in coordination of services related to both palliative and respite care.

- Leverage collaborations through public-private partnership to provide respite services.
- Support programs that address families' many needs that are not traditionally covered through other funding sources, such as respite care and recreational support that help support overall family health and well-being.

FINANCING

- Pursue a combination of approaches to financing and operate some type of pilot. A variety of support services, from trust funds to care coordination to benefits counseling, may help alleviate the financial burden on families.
- Explore the state Medicaid benefits package and determine if it currently meets the needs of CY-SHCN, and whether it could offer an enhanced benefit package or a bundle of services for those with chronic illnesses and disabilities.
- Create a Medicaid Buy-In Program through the Family Opportunity Act that may represent an overall worthwhile and cost-effective intervention if the Medicaid package is relatively robust.

HEALTH INFORMATION TECHNOLOGY

- Invest in a statewide CYSHCN registry. Current registry models are adult-focused and there is currently no strong pediatric models for EMRs or registries. Developing CYSHCN registries can help providers better follow their patient load. This could be in combination with the development of a stronger Electronic Medical Record model.
- Ensure that investments in health information technology software for coordinating the care of CYSHCN are transferable across states.