

Children and Youth with Special Health Care Needs (CYSHCN) Workgroup

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Rhode Island Medicaid Global Waiver Task Force

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This work group, which had been originally defined as the “Katie Beckett Work Group” is now identified as the Children and Youth with Special Health Care Needs (CYSHCN) Work Group, as there are many more children and youth in our state with special health care needs who rely on Medicaid funding for the services and supports they require to be cared for in their own homes and communities. The work group did agree to begin our work focusing on the two primary areas that the state had identified as needing immediate attention, one of which would include a proposal by the state to impose “cost-sharing” on families who have a child or youth only eligible for Medicaid by way of the “Katie Beckett” provision, also known as the TEFRA program. The other area of priority interest to the state uses the promotion of more self-directed services to this population of children and families.

Data was shared with the group by DHS identifying the Katie Beckett eligible population in the state as currently 1419 children and youth, identifying 155 aged birth to 4 years, 450 aged 5 to 9 years, 478 aged 10 to 14 years, and 336 aged 15-19 years. These are children and youth who meet the Supplemental Security Administration’s definition of childhood disability but whose families are over income for Supplemental Security Income. The children and youth qualify for Medicaid eligibility as they also meet a level of institutional care but are being cared for at home and in their communities and only the income/assets of the individual are considered. Without the services and supports that they are eligible to access exclusively through their Medicaid eligibility, they would be at risk for out of home placement, leaving them totally dependent on Medicaid to pay for their health services. Of the 1419 children and youth identified, 1339 or 94% of them have access to third party liability insurance through commercial insurance available through their parents’ employers, leaving Medicaid only responsible for any out of pocket costs not covered by their commercial insurers. Those with TPL are not eligible to access their Medicaid through managed care due to their commercial insurance status. This population is “carved out” of accessing managed care. Conversely, only six percent of this population rely on 100% of their costs to be covered by Medicaid and are, therefore, mandated into one of the RIte Care health plans. These children and families live in almost

every city and town in the State of Rhode Island with the most (167) residing in Warwick and living with families with a wide range of income and assets.

Again, the child or youth's Medicaid eligibility is based on his or her individual income and/or assets only, as mandated in federal TEFRA law.

The RI Annual Medicaid Expenditure Report – STATE FY 2008 (pg. 42) includes Medicaid data exclusively related to Children with Special Health Care Needs in the state but does not specifically break down the data for those children eligible through the Katie Beckett provision, leaving this work group with extremely limited population specific data to work from. We have requested a side-by-side analysis comparing Katie Beckett data to overall data to be clear about what is currently being expended by this unique population and, of that, how much is being covered through TPL. We are awaiting more specific data to be able to make fully informed recommendations regarding any “cost sharing” proposals and believe that costs to these families must be an absolute last resort as they are already significantly contributing to their children's' health expenses through co-premiums, out of pocket expenses not covered by either commercial insurance or Medicaid and many are, in fact, underemployed or unemployed due to the demands of caring for their children at home. One or both parents often have to limit their work hours to meet the complex needs of these children.

The Katie Beckett eligibility provision of Medicaid under TEFRA has proven itself to be a safety net for more than 1400 children and youth in RI. We must not compromise this safety net that helps us to provide for our children in our homes and communities.

REVENUE GENERATION:

MAXIMIZE COMMERCIAL DOLLARS

Accountability

What is the role of the Health Insurance Commissioner (OHIC)?

Enforcement with sanctions on commercial insurers when warranted.

Children's Health Account – increase from \$5K to \$6K/insured child annually.

Explore Medicaid “buy-in” option for families whose children meet the SSI definition of childhood disability but do not meet “Katie Beckett Level of Care,” to allow them equal access to CEDARR Family Centers and CEDARR Direct Services. Most of these families have commercial insurance but need the wraparound coverage not currently available to them to care for their children at home, in communities.

Assist CEDARR Family Centers in developing reimbursement procedures from all insurers and require those insurers to cover CEDARR services.

Re-evaluate current state agency structure under EOHHS – abundance of short staffed buildings – consider physical consolidation of agencies, not losing agency identity, but housed more efficiently to reduce operational expense to the state (i.e. utilities, maintenance, etc.), encouraging true collaboration by physically working more closely together. Current structure is no longer sustainable considering state budget crises.

Explore tax structure: Consider elimination of tax cuts for higher income populations currently in effect.

SYSTEMS OF CARE/MEDICAL HOMES

More than 12 million (13.1%) children and youth in the United States have a special health care need. The U. S. Maternal and Child Health Bureau and the American Academy of Pediatrics recommend that all children receive care in a medical home. Medical homes improve health outcomes for children with special health care needs. They provide care that is clinically effective, timelier, and more family centered than other sources of care. Further research must examine the impact of this model; use consistent definitions and outcome measures; and explore the types of supports that are needed to create and sustain medical homes over time. These values are reported by the Massachusetts General Hospital Center for Child and Adolescent Health Policy.

Policy makers must assess state performance, fully partner with consumers and providers, provide training and support, develop incentives and support true care coordination.

As stated by William E. Schwab, M.D., Professor, Department of Family Medicine at the University of Wisconsin, "...Medical Home is an innovative quality improvement strategy for pediatric chronic conditions using a collaborative self-management model to provide safe, effective, patient- and family-centered, timely, equitable care. It can improve clinical outcomes, optimize resource utilization, and increase family and provider satisfaction."

Maintain Rite Care/Rite Share infrastructure as medical home model proven to be cost effective with better outcomes for children and families and must be built upon.

Improve access to "self-directed" models of care (i.e. PASS, others)

Simplify access

Educate families about this option (Outreach)

Explore various methods of better utilizing this model

Explore strategies that are realistic for families to use and cost-effective

Must be kept optional versus mandatory – does not work for every family

Clarify how newly developed (and now Medicaid matchable) FCCP will integrate and fully collaborate with already established CEDARR Family Centers. CEDARR must play a role with these Family Care Community Partnerships (Family Care Community Partnerships (FCCPs)) and be incorporated into DCYF's Phase Two concept paper (Draft September 2009). There is considerable concern of duplication and reverting back to separation and competition among and between disability groups. RI made a commitment to ALL children and families through its Leadership Roundtable, in existence for more than a decade, and development of CEDARR Family Centers. The following is the Vision Statement created by the state's Leadership Roundtable for Children with Special Needs:

“All Rhode Island children and their families will have an evolving, family-centered, strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities.”

NO further cuts to providers of CEDARR Direct Services. These are the services and supports that have kept many of our children OUT of institutions and in their communities and are working for children and families. As these cuts manifest, our children are at considerable risk of out of home placement, far exceeding costs for care at home. Little, if any, alternative placement options exist in this state. Many of these children will ultimately be at a much higher risk of hospitalization and/or be forced into state care for extended periods without stable home care supports in place.

Information and targeted outreach is needed on available respite services. Many families could manage with lower intensity services and supports but have no other option but to access higher levels of care.

Promote natural supports to include family support through family-run organizations, neighbors, church members, coaches, etc.

Continuum of care must include home and hospice care when appropriate.

COST SHARING/SHIFTING

The state must thoroughly research and explore potential additional cost sharing for families whose incomes are above a specified income level (yet to be determined), with consideration of the research study, **“Material Hardship in US**

Families Raising Children with Disabilities: Research Summary & Policy Implications”

(<http://bhrp.sowo.unc.edu/susanparish/files/Material%20Hardship%20children%20with%20disabs.pdf>). Consideration must be given to parents’ “employability” limitations while caring for children and youth with special needs and resulting decline in earning potential. Research documents that many are underemployed or unemployed due to meeting the needs of their children in the home and community. This needs considerable further research and dialog to reach consensus on fairness and sliding scale considerations. How is “fairness” being defined? And by whom is it being defined? Affordability must be a significant consideration, not based on family income only. National research (i.e. The Catalyst Center, Community Catalyst, others) regarding definitions of affordability has been completed and published and must be considered before specific recommendations can be made. “Spend down” consideration – is there a standard formula in place in Medicaid law? How is it applied? Explore feasibility of family’s commercial insurer being assessed any cost sharing component. Cost shifting must not fall to families OR their employers through increased commercial insurance premiums (involve OHIC). We have research from several states, including Idaho, Georgia, Maine, Minnesota and others that must be thoroughly reviewed and analyzed before recommendations can be made. This work group CANNOT endorse any implementation of this component without further research.

This work group cannot make specific, responsible budget recommendations without identified (by EOHHS) targets to reach. Co-premiums/co-shares should only be considered as a last resort.

Explore both benefits and challenges of utilization of “Para-professionals” to provide direct care at lower costs.

QUALITY ASSURANCE:

CYSHCN Leadership Roundtable: More than a decade of experience/expertise bringing families, providers, policymakers and state government together to share experiences, identify successes and challenges, identify solution oriented, consensus building action steps. This venue cannot be abandoned. This collaborative process has a proven track record of identifying and acting upon system challenges and improving outcomes for children and youth with special health care needs.

The state must work toward SEAMLESS transitions to adult systems of care with no gaps in service/supports due to systems differences. We may need to consider something similar to Individualized Education Program (IEP) but including health care and work options. We must work collaboratively with other state agencies serving this population currently not under EOHHS authority (i.e.

Department of Health, Office of Special Health Care Needs; Department of Education, Office of Special Populations, etc.).

Evidence-based quality assurance, monitoring and oversight that include timelines, access, and appeals processes clearly identified and communicated to families.

VALUE STATEMENTS:

FAMILIES AND YOUTH MUST HAVE VOICE AND CHOICE

Individual and/or family driven

Informed families make informed choices

Cultural & linguistic competencies

PROTECT TEFRA (KATIE BECKETT) ELIGIBILITY OPTION

Equitable access to quality care for ALL RI children and youth with special needs and their families, not only those currently eligible for Medicaid.

System(s) must be built on family strengths.

Timely access to service and supports – wait lists do not work, only put more strain on families leaving them more vulnerable to poor outcomes.

CONCLUSIONS:

Children and youth services represent a very small portion of the overall Medicaid program in RI but their needs are vitally important and society has a moral responsibility to care for those less fortunate. Our work group has significant concerns that because this is such a small population, our children and families' needs may be overlooked as the state continues its work to design, implement, and monitor the Global Medicaid Waiver. The Leadership Roundtable has been the only venue to oversee and contribute to policy discussions impacting these vulnerable populations of children and families. We believe that the integrity of this important work group be maintained to ensure that we continue to work progressively to improve outcomes for all children and families, including those with special needs.