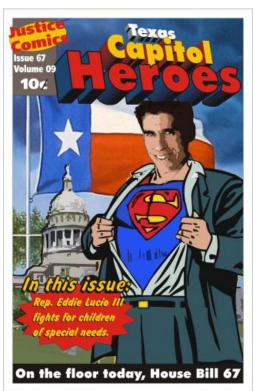


Buying into a Medicaid Buy-in Program: The Texas Experience

Texas legislative staff agree: family advocacy was the spark that pushed the Medicaid Buy-in program for children with disabilities from an idea to a reality. Senator Bob Deuell and Representative Eddie Lucio III, the Texas state legislators who each sponsored a Medicaid Buy-in bill were both inspired by the experiences of individual constituents. Senator Deuell is a family physician who, according to staff member Scot Kibbe, often hears stories of financial hardship and medical debt from his patients. Representative Lucio III was motivated by the experience of a close personal friend whose daughter has Down Syndrome.

The process of passing the bill through the legislature began in 2005 when the Texas legislature passed a Medicaid Buy-in Program for adults with disabilities. Learning about the advantages of a Medicaid buy-in program for adults fostered understanding of the concept and proved that the idea could receive adequate support in Texas. Although the stage was set, fiscal conservatives who were concerned about costs and the economy did not support the parallel bill for children. In 2007, the bill was heard in the House of Representatives but never brought to a vote. The two-year cycle of the Texas legislature meant that the bill could not be reintroduced until 2009. During the interim, advocates and legislators who supported the bill were not idle.



Texas representative Eddie Lucio III depicted as a superhero for championing Medicaid Buy-In for CYSHCN.

The Family Opportunity Act's Medicaid Buy-in Option

This Medicaid Buy-in program allows individuals or families whose adjusted gross income is up to 300% of the federal poverty level (approximately \$72,900 for a family of four) to pay premiums to access Medicaid. Normally these families would not be eligible because their income is too high. Through the Medicaid Buy-In for Children (http://www. hhsc.state.tx.us/help/healthcare/MBIC.shtml) program, they can use Medicaid as their only insurance or to supplement any private health insurance policy. The Family Opportunity Act allows states to provide this program for children who meet SSI disability criteria (https:// www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm). This program not only alleviates family financial hardship, it also provides an incentive for families to keep their private coverage, because they can still get the more comprehensive benefits of Medicaid for their child with a disability. Without this program, families may cut back on work in order to become eligible for Medicaid. According to the National Survey of Children with Special Health Care Needs (http://childhealthdata.org/learn/NS-CSHCN), 13.4 % of children in Texas have a special health care need. Almost 24% of these families spend \$1,000 or more in out-of-pocket medical expenses for their child. Twenty-seven percent of families of children with special health care needs report that a family member cut back or stopped working to care for their child.

Learn more about Medicaid Buy-in programs at http://cahpp.org/project/the-catalyst-center/financing-strategy/medicaid-buy-ins/

In 2009, parent advocates organized a more comprehensive effort and increased the intensity of their educational outreach activities. Organizations such as Down by the Border, the Children's Policy Council, the Disability Policy Consortium, the ARC of Texas, the Coalition of Texans with Disabilities and others educated legislators and increased awareness of the need for a Medicaid Buy-in program to help alleviate family financial hardship and help children access the care they need.

Sergio Zarate, one of the founders of Down by the Border, said that for a month he would go to the capitol on a Sunday and spend two days visiting legislators. With him, he brought two items: a photograph of his daughter who has Down Syndrome and a comic book cover that depicted each representative and senator as a "hero." Zarate said that although it was hard to go to the Capitol and tell your private story, it is what opened doors.

Texas Parent to Parent, in conjunction with Family Voices and the Texas Parent Advocacy Coalition, organized a family summit to educate families on Medicaid Buy-in and advocacy. The Texas Parent Advocacy Coalition and Texas Parent to Parent both used listservs to communicate with families and mobilize them at key points in the legislative process. In this round of advocacy, Charlie Leal, Legislative Director for Representative Lucio III, says that supporters changed their emphasis. In 2007, advocates mainly focused on conveying the needs of families. In 2009, they told legislators that "this program will be helping people who are working themselves. If they guit their jobs they would have all of the services that they need."



Buying into a Medicaid Buy-in Program: The Texas Experience, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, September 2009, Updated July 2016.

While parents helped illuminate the need for and the logic of the Medicaid Buy-in program, the Department of Health and Human Services revised their prior estimate of the cost. Other states' experiences showed that the cost per child was not as high as had been previously forecast, and many families were using Medicaid coverage as secondary insurance to cover those expenses that their private insurance didn't cover. Additionally, the Medicaid Buy-in program for adults had very low enrollment, indicating that not everyone who was eligible would sign up.

After months of lobbying, the Medicaid Buy-in program for children and youth with special health care needs passed in Texas in May 2009. But the work in making it a reality for Texas children and families was not yet finished. The next challenge was to obtain a state budget funding allocation; without funding there would be no program. The efforts of all involved paid off, and legislators voted the program was worth the cost. The state now has twenty million dollars approved for the first two years of the program with a projected budget of sixty million per year beginning in 2014; the program is estimated to eventually serve 6,207 children with severe disabilities. Zarate and other advocates thanked the legislators for their hard work at a September reception.

On September 1, 2009, the Texas Department of Health and Human Services began the administrative process. In September 2010, families of children who meet the SSI disability criteria whose income is less than 300% of the federal poverty level can purchase Medicaid coverage.

Congratulations to Senator Deuell, Representative Lucio, and all of the parent advocates and organizations!

Is your child with a disability eligible for the Texas Medicaid Buy-In program?

- Learn about eligibility and application (English and Spanish) at the Texas Health and Human Services Commission website (http://www.hhsc.state.tx.us/help/healthcare/MBIC.shtml).
- If you have questions or need assistance, Texas Parent to Parent (http://www.txp2p.org/), the state Family-to-Family Health Information Center, can help.
- Visit our Information for Families page (http://cahpp.org/projects/the-catalyst-center/info/#TX) for more Texas organizations that assist families raising CYSHCN.



Take home messages

On FOA Buy-in programs:

- Medicaid Buy-in programs can help reduce uninsurance and underinsurance in children and youth with disabilities.
- Medicaid Buy-in programs support families who may otherwise feel compelled to cut back on work in order to become eligible for Medicaid.
- The Catalyst Center can create a cost estimate for a Medicaid Buyin program in your state.

For health care financing advocates:

- How you frame a proposal can make a difference include all sides
- The legislative process often moves very slowly. Be prepared for the long haul.
- Personal stories really make the difference!

The Family Opportunity Act's Medicaid Buy-in Option:

This Medicaid Buy-in program allows individuals or families whose adjusted gross income is up to 300% of the federal poverty level (approximately \$72,900 for a family of four) to pay premiums to access Medicaid. Normally these families would not be eligible because their income is too high. Through the Medicaid Buy-In for Children (http://cahpp.org/ resources/?keyword=medicaid-buy-in-programs&sort=date-desc) program, they can use Medicaid as their only insurance or to supplement any private health insurance policy. The Family Opportunity Act enabled states to provide this program for children who meet SSI disability criteria (https://www.ssa.gov/disability/professionals/bluebook/Childhood-Listings.htm). This program not only alleviates family financial hardship, it also provides an incentive for families to keep their private coverage, because they can still get the more comprehensive benefits of Medicaid for their child with a disability. Without this program, families may cut back on work in order to become eligible for Medicaid. According to the National Survey of Children with Special Health Care Needs (http://childhealthdata.org/ learn/NS-CSHCN), nationally, 15.1% of children have special health care needs. More than 22% of families spend \$1000 or more in out-of-pocket medical expenses for their child. Twenty-five percent of families of children with special health care needs report that a family member cut back or stopped working to care for their child.



About the Catalyst Center

The Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs is a national center funded by the Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, and is located at the Boston University School of Public Health. The Catalyst Center provides support to the efforts of stakeholders at the federal, state, and local levels in assuring adequate health insurance coverage and financing to meet the diverse needs of children and youth with special health care needs and their families.

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