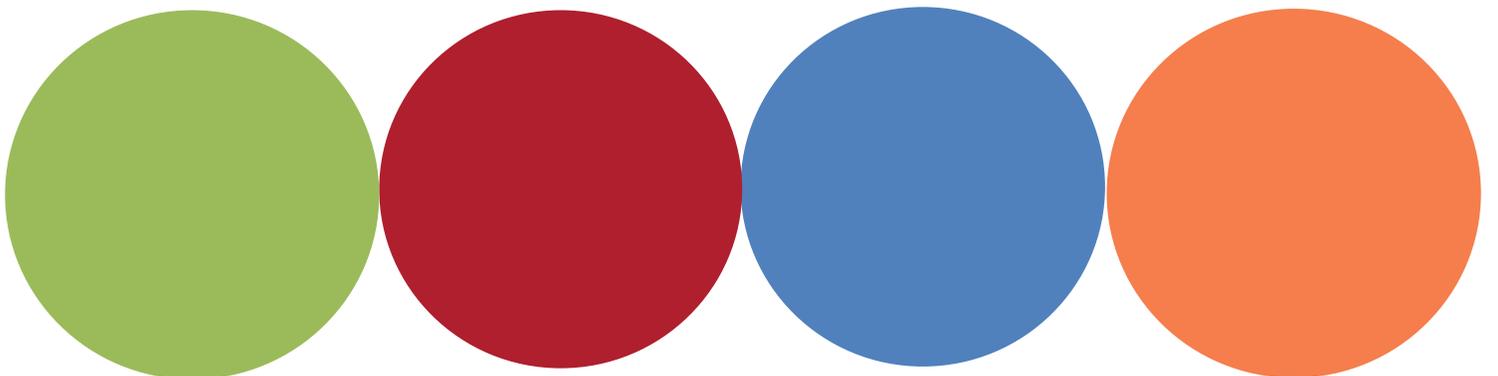


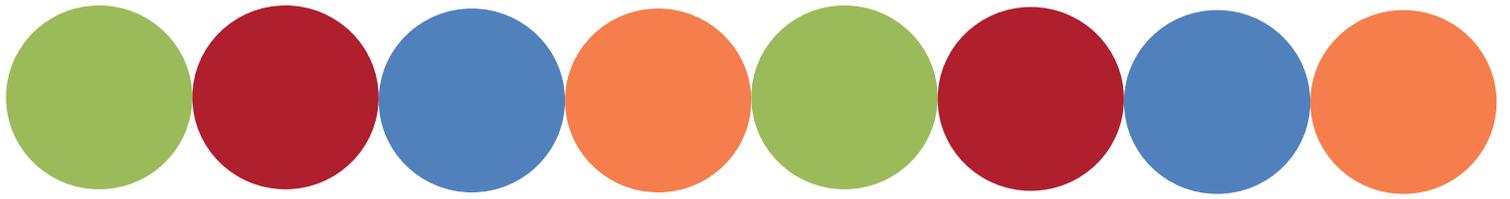
CHIP and Medicaid: A Utah Success Story



January 2018

Voices for Utah Children would like to thank the Utah families, parents and children who have shared their story. They have bravely come forward to share how Medicaid and CHIP changed their lives. We would also like to thank the many partner organizations who have collaborated with us on this project including the Utah Health Policy Project, the American Academy of Pediatrics- Utah Chapter, Utah Family Voices, Comunidades Unidas, and many other organizations. Many thanks to all for their time and efforts.





Historic Progress for Children's Coverage

Since the creation of Medicaid in 1965, chartered to provide health care to poor children, and the creation of CHIP in 1997, to cover children in low-income working families, these investments have delivered cost-effective, high-quality health coverage to millions of Utah kids. We have seen the benefit to Utah beyond health care: children with health insurance coverage are not only healthier, they also miss fewer days of school and their parents miss less work; they perform better in school and achieve higher-earning jobs later in life. Investing in children's health care is investing in Utah's future.

The following stories celebrate the families of CHIP and Medicaid. These stories highlight the critical role that CHIP and Medicaid play for families from across our state and all walks of life. In their own words, families share how CHIP and Medicaid helped them overcome significant challenges to their children's health and their family's well-being. These stories are a celebration of families', as well as CHIP and Medicaid's, success.

Thanks to CHIP and Medicaid, we have made historic progress insuring children in Utah and in our nation. More children have health insurance coverage in Utah than ever before. It is critical that we continue to build on these gains, so that no child in Utah is without health insurance. While we have made progress, we still have work ahead; thousands of children are still without health insurance. CHIP and Medicaid provide the foundation for our continued success, so that all Utah children can be healthy and thrive.

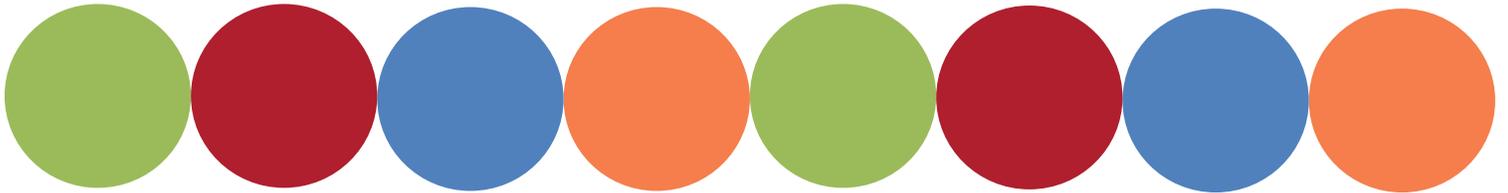
My daughter was born with 12 toes and thanks to Medicaid, we could afford the surgery.

I remember when we got the medical bill back from the hospital after her surgery. My husband and I sat down and braced ourselves. Then we opened the bill- it was a miracle. We didn't have to pay for her surgery. We could've have afforded it otherwise.

-Christy



“We couldn't have afforded my daughter's surgery otherwise.”



With both the Chip and Medicaid programs we have been able to get our kids to their check-ups, get their vaccines, be able to visit the doctor when they got sick. If we did not have these programs for our girls we would not have been able to take them for any of those things. When my youngest got sick at 6 months old I was so relieved and comforted that I was able to take her to the doctor and get her medicine without stressing about where to get the money we didn't have to cover those bills. Both programs have helped up to stay away from debt during our kids' illnesses.

-Jasmine H.

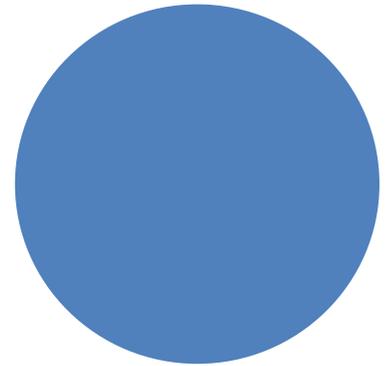
“Both programs have helped us to stay away from debt during our kids' illnesses.”

Thanks to this program [my children] have maintained good medical attention and even surgeries. I take care of my children. I arrived here with my sisters and nephews from Ecuador all together. Thank God we're together.



The payment of the insurance is economical and has very good benefits. This insurance is key for our children.

-Maritza (mother of 3)



I have 2 sons, one of which is on a Medicaid Waiver. My son has Cystic Fibrosis (CF) and Cerebral Palsy (CP). Having both has been a challenge, the CP makes it so he is unable to do enough exercise to help with the CF. If we did not have Medicaid, my son would be dead. That sounds a bit dramatic, but it is the case. His formula alone is \$4500 a month. His medications are an extremely substantial amount. Even when having private insurance, the deductible is more than my family can afford. Even with my husband and I both working. Please make choices that will keep my son alive and healthy.
- J.H.



“If we did not have Medicaid, my son would be dead. That sounds a bit dramatic, but it is the case.”



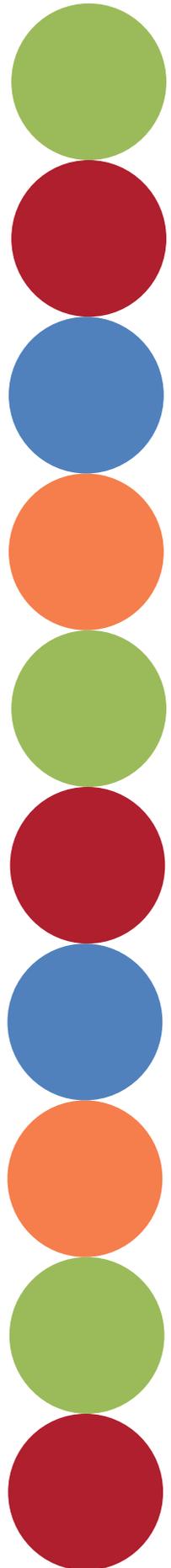
Our family has 3 children with special needs, all of them came to our family through adoption. Oliver is 4, Christopher 2 and Rachel is 6 months. Before Oliver's diagnosis we were a 2 income family, with me earning the higher income. My husband and I worked opposite shifts, opposite days. You could say we were living the American dream. 2 cars a house and life was good. Oliver required many therapy and Dr visits, and I had to cut down my hours. However we didn't qualify for any assistance like Medicaid or social security for him due to our income. We also did not make enough money to pay for his expensive medical bills.

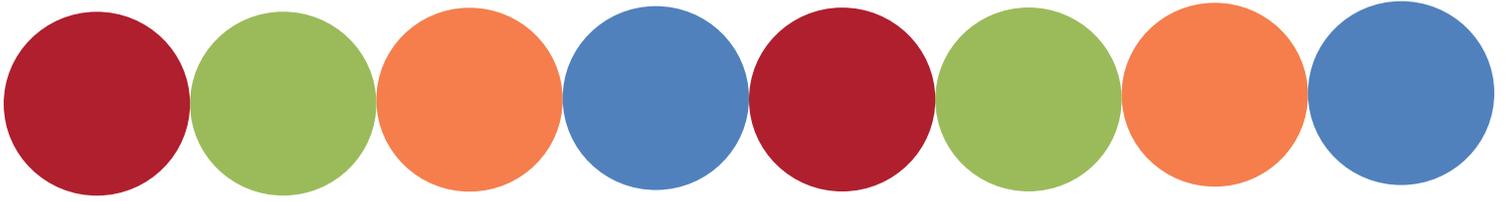
We ended up declaring bankruptcy to try to get ahead.

Then Christopher joined our family, his needs are more severe and required many many hospitalizations, some we didn't know if we were ever going to be able to bring him home. I had to quit my job, and my husband had to take a lot of time off from work so that while we were in the hospital he could watch the other kids. Bills were coming in faster than we could afford. With the loss of my job, and the majority of our income things became very hard for us. We lost our house and had to move in with family. We sold everything of worth. This is when the Medicaid Medically Complex Children's Waiver (MCCW) became available for us. It literally was a lifesaver. We were able to afford the medical bills, we did have primary insurance however it had a very high deductible. We have been able to get much needed equipment for my children like medical beds and adaptive strollers as well as many therapy visits. Also now their very expensive formula is now covered. The MCCW had given us freedom from medical debt. We are currently looking into buying a house and none of that would be possible without the MCCW. Please continue to fund this much needed program.

- Melanie B.

"The Medicaid Medically Complex Children's Waiver (MCCW) literally was a lifesaver"





“Our son’s care is still challenging; he still has all of the same health conditions and risks as he did two years ago. However, it all seems to be so much more manageable thanks to Medicaid and the waiver. “

Our son was born with an ultra rare genetic mutation and he is one of only 6 children in the world with his genetic syndrome, which doesn’t even have a name yet. Besides living in a hospital and fighting to keep our child alive, our first couple of years of his life were filled with financial devastation due to medical expenses. We meet our deductible and family out of pocket maximum within 1-2 months of our plan renewing every year. Then there are many expenses not covered by insurance such as sleep studies, prescriptions, and therapies which added another several thousand dollars of expenses onto our premiums, copays, deductible and maximum out of pocket. When you care for a medically fragile child, things rarely calm down. I saw an old note from 2014 documenting that in that year we had 56 doctors’ appointments, 2 hospital stays, 4 surgeries, 8 ER visits, 1 sleep study, 1 CT scan, 1 MRI, 32 therapy appointments outside of the home and another 73 therapy appointments in our home. We traveled a total of 4,840 medical miles. This is honestly an average year for us. It only took living this life for 3 years to see how quickly we would lose our home, take out bankruptcy and lose everything we worked so hard for. We were already behind on many bills, had more expenses and medical bills than income, charged almost \$10,000 onto our credit card for living expenses and prescriptions, and did not see an end to this trend. My husband and I both have college degrees and post-graduate degrees, and both of us work in professional careers. Even so, we could not afford the costs of caring for a medically complex child.



In November 2015 our family experienced one of the greatest blessings—our son was accepted onto the Medically Complex Child Waiver here in Utah. It literally changed everything. In just a year and a half of being on the waiver, we have been able to pay off all of our medical debt and credit card debt. We are caught up on our bills and feel comfortable again. We were able to afford to grow our family and are currently expecting a baby girl in June thanks to the miracle of invitro and donor embryo adoption. We no longer lose sleep or become physically ill over the financial aspects of caring for our son.

Absolutely anyone can give birth to a medically fragile child. This type of financial burden and devastation could happen to anybody in our situation. All we are trying to do is care for the special child God gave us. We did not ask for this challenging life and we certainly don’t expect handouts. We just need some help to keep our family afloat and keep our child alive. Please do all you can to continue funding for Medicaid for medically fragile families! Without it children and families will truly suffer. Children lose medications, therapies, services, and necessary procedures. Parents lose their homes, jobs, raises, and mental health. We need to continue care for our most vulnerable populations.

- W. Family

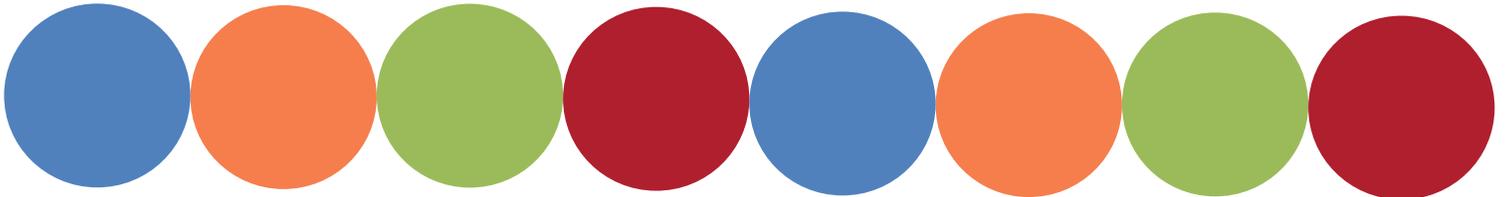
“...She endured a number of life-saving medical procedures... Medicaid made [them] possible.”

“Katelyn was born, June 11, 2014, at 29 weeks premature... and was life-flighted to Primary Children’s Hospital where she was a patient in the NICU for two and a half months. During this stay she endured a number of life-saving medical procedures, including emergency surgery on her belly at five-days-old, and her first open-hear surgery at one-month-old, all procedures Medicaid made possible.

When Katelyn finally came home, we needed expensive Home Medicaid Care and medical equipment to help care for her. Thanks to the help of Medicaid we were able to get those things.

...If we were to lose Medicaid, we do not know how we would be able to pay the medical care our now three-year-old daughter needs to live a full, happy and productive life.”

-Rebecca J., mother of Katelyn

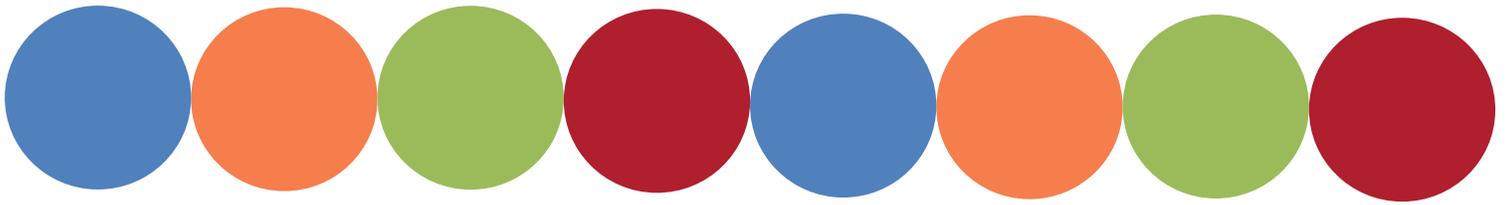


“I have epilepsy and have to be medicated always and about 7 years ago didn’t have insurance so I wasn’t medicated so I was having 3 or 4 seizures about every day and because of that I have very few memories and can’t even remember things very well. I can’t even remember my children’s births. But I have gotten on Medicaid and now have the medication I need and can be around my kids and spend time with them without worrying. Instead of paying \$500 or more a month I am able to spend money on my family and be alert around my kids and we can live our lives by ourselves and make memories together.”

- Sierra C.



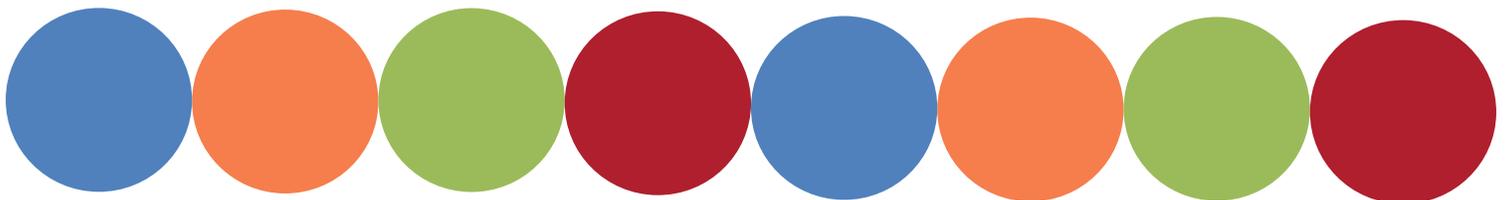
“I am able to...be alert around my kids and we can live our lives by ourselves and make memories together.”

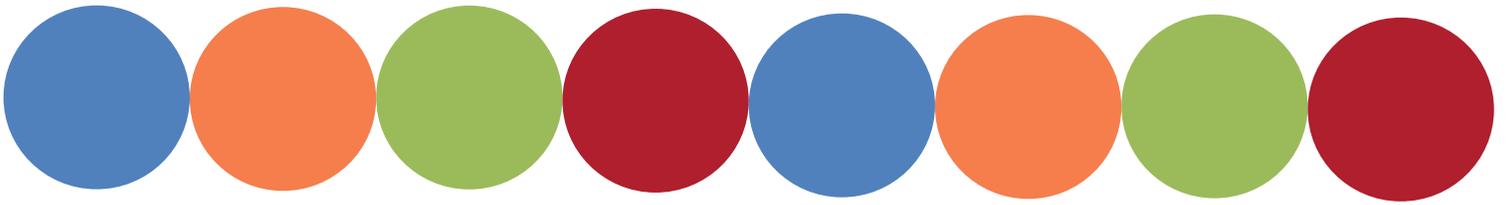


When our second son was born with a genetic disease that required hundreds of doctor visits, expensive tests, stays in the hospital, even an emergency helicopter transport, Medicaid made all the difference in allowing us to receive that care our son so urgently needed without having to destroy our lives trying to pay for it. It has given us such peace of mind to know that we can get our son the help he needs and still be able to pay our rent and provide food for our children. It has also allowed us to get our son the therapies he needs to improve his cognition and learning. We have not had to make the difficult choices between what help we can afford to get our son and what help he just doesn't get to receive because we can't pay for it. Our children can thrive because we don't have to skimp on either their health care or our basic needs. Medicaid is the tool that makes our son's condition bearable. We can help him without giving up everything else. My husband has a normal entry level full time job, starting his career after college just this year. He doesn't make a lot right now, but he works hard for his company. I stay home to care for our two children. We try to live frugally and not go into debt. We prioritize the important things like family and community. But without Medicaid, we'd be floundering in debt. We wouldn't be able to spend time together as a family as we would have to work more jobs to pay for our needs. Without Medicaid, our son's disease would be breaking our family. Instead, we can pull together and help him and each other, because Medicaid helps us.

-Krista B.

“Without Medicaid, our son's disease would be breaking our family. Instead, we can pull together and help him and each other, because Medicaid helps us.”





Jax was ...in the NICU at the hospital because he was premature and his lungs were underdeveloped. He also had difficulty eating and was moved to sensitive formula while still in the NICU... our pediatrician asked us about Medicaid. She didn't know all the details but helped us find the necessary information and it was their home medical advocate that helped us get Medicaid.

Medicaid allowed our son to get the necessary care, find the cause of his medical issues, and supplement the cost of our formula... The only formula that Jax could tolerate and where he began to thrive on was a specialty formula that is used for children that are tube feed. Jax was capable of eating, just not digesting or processing food. Therefore, insurance would not help cover the cost of the formula. When he was solely on formula it would have been well over \$1200.00 a month just for formula. That is more than my entire monthly income. We still needed to feed the rest of our family, pay childcare, and bills. It was just not possible on my husband's income. We are blessed with family that can help and we discussed selling our home again and moving back into the basement. Yet, because we could get Medicaid we were able to continue living in our 2-bedroom home.

...The stigma of those on Medicaid in society tends to be that they are "living off the government" and that is not necessarily true. I have a Masters of Education and work in the public school system while my husband works full time or more as a General Manager. The costs that were occurred due to our son's medical needs were out of the norm. Without Medicaid we would have been more of a burden to government programs and likely would have claimed Medical bankruptcy. Instead, with short term assistance not only were we able to get the best medical help for our son, we were able to continue financial supporting our family and contributing to society and paying taxes.

-Courtney B.



"Medicaid allowed our son to get the necessary care... Without Medicaid we would have been more of a burden to the government programs and likely would have claimed Medicaid bankruptcy"

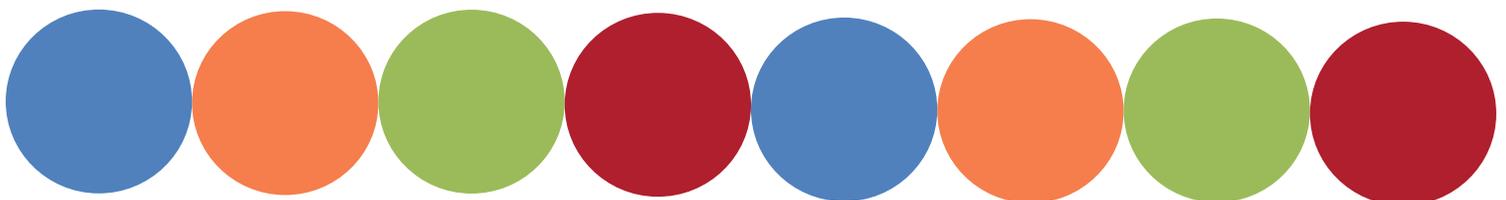
Sources of Children's Coverage, Percentage of Children, 2011-2015

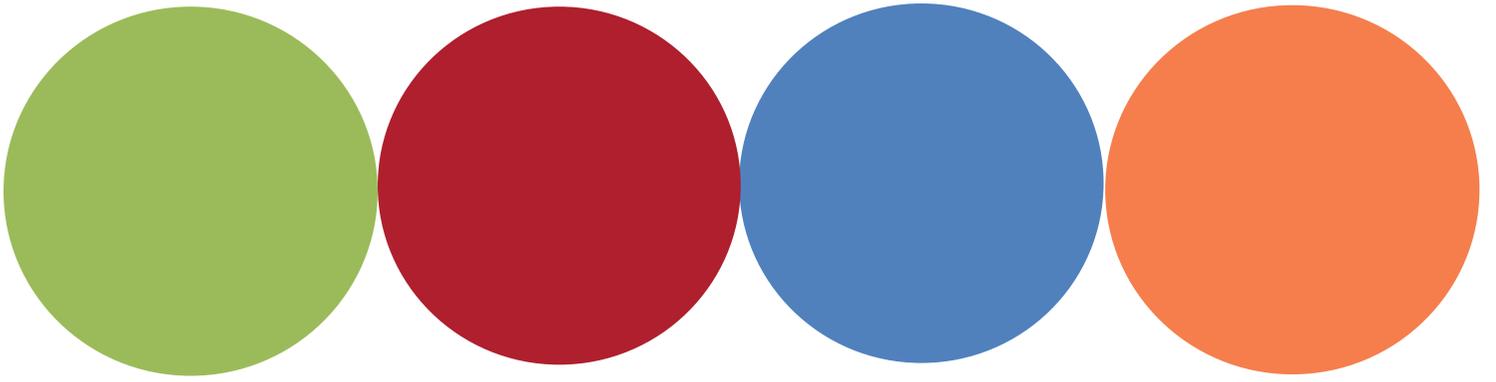
	Percent of children with Medicaid/CHIP	Percent of children with ESI*	Percent of children with direct purchase	Percent of children with other coverage	Percent of children who are uninsured
Beaver County	10%	68%	7%	4%	11%
Box Elder County	12%	68%	8%	8%	4%
Cache County	18%	59%	10%	7%	6%
Carbon County	23%	61%	2%	7%	7%
Daggett County	16%	59%	19%	6%	0%
Davis County	13%	68%	6%	8%	5%
Duchesne County	12%	66%	5%	5%	12%
Emery County	20%	61%	1%	7%	11%
Garfield County	12%	58%	3%	13%	13%
Grand County	26%	40%	4%	2%	28%
Iron County	24%	47%	8%	7%	15%
Juab County	21%	59%	2%	5%	12%
Kane County	15%	49%	8%	6%	22%
Millard County	25%	55%	4%	4%	12%
Morgan County	11%	70%	10%	3%	7%
Piute County	18%	37%	5%	19%	21%
Rich County	21%	64%	2%	3%	10%
Salt Lake County	18%	60%	6%	6%	11%
San Juan County	37%	35%	5%	4%	19%
Sanpete County	21%	52%	6%	7%	13%
Sevier County	23%	54%	4%	6%	12%
Summit County	9%	68%	11%	4%	8%
Tooele County	12%	72%	3%	5%	7%
Uintah County	14%	61%	8%	7%	10%
Utah County	14%	63%	8%	6%	8%
Wasatch County	11%	54%	15%	9%	11%
Washington County	25%	42%	8%	8%	17%
Wayne County	10%	53%	1%	21%	16%
Weber County	18%	59%	6%	8%	9%

Source

Five-year estimates of summary data from the 2015 American Community Survey (ACS). The U.S. Census Bureau publishes ACS summary data on American Fact Finder. Percent estimates were computed.

*Employer Sponsored Insurance





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