Report to the Health and Human Services Interim Committee

Medically Complex Children's Waiver Pilot

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UTAH DEPARTMENT OF HEALTH MEDICAID

Medically Complex Children's Waiver Executive Summary

The Department of Health (Department), in collaboration with multiple stakeholders, designed the Medically Complex Children's Waiver (MCCW) Pilot Program. The State submitted the MCCW application to the Centers for Medicare and Medicaid Services (CMS) on June 30, 2015. CMS approved the MCCW with an October 1, 2015 effective date. The MCCW serves children with disabilities and complex medical conditions who are between 0 – 18 years of age.

The eligibility criteria for the program requires children to have a level of medical complexity based on a combination of conditions that involve multiple organ systems, require use of multiple specialty physicians, require high utilization of medical therapies and treatments, and need frequent medical intervention and device-based supports. A child must also have a level of disability determined by the State Medical Review Board or the Social Security Administration. Since its implementation, the MCCW has served 341 children statewide. Children were enrolled during two open enrollment periods; October 2015 and May 2016. In total, the Department received 472 applications for this program.

With the passage of House Bill 199 during the 2015 General Session, beginning November 2016, the Department is required to submit an annual report to the Health and Human Services Interim Committee on the number of qualified children served under the waiver, the effectiveness and the cost of the program.

Outcomes and Effectiveness

The MCCW was established to address an array of significant issues that families caring for children with complex medical care needs must confront. Families caring for medically complex children frequently experience substantial financial hardships due to the high cost of medical treatments, equipment, and supplies. Financial issues also include job loss or reduction of parental income related to the time-intensive nature of caring for a child with complex needs. In addition, families experience pervasive emotional stressors as well as strained relationships with a spouse or other children in the family.

To evaluate program effectiveness in addressing these issues, the Department conducted a baseline survey with each family upon the child's enrollment in the MCCW and a follow-up survey after the child had been participating in the MCCW for six months. Survey results after six months of participation where positive and showed improvement in several key areas.

Improved Outcomes for Families after Six Months in MCCW

Financial Stressors

- **Reduced medical debt**
- **Increased ability to pay for basic household necessities (food, housing, utilities)**
- **Improved employment – increase in number of hours worked or ability to get a job**
- **Reduced need to forego or delay child's needed treatment**
- **Reduced out of pocket medical expenses**

Caregiver Emotional Stressors

- **Decreased feelings of isolation**
- **Reduced feeling of neglecting other important family relationships (such as spouse or other children)**
- **Increased ability to cope with caring for a medically complex child**
- **Decreased feeling of being completely overwhelmed**

In both initial and follow up surveys, roughly 82 percent of families reported that in addition to Medicaid coverage provided by the MCCW, the child had primary insurance coverage through a private insurance company. Although families reported primary insurance coverage, many still described that they incurred significant medical debt in order to access treatments and services not covered by their primary insurance, or to cover costs associated with copayments or coinsurance. Survey results showed that after six months in the program, the average amount of debt incurred dropped by 68 percent and families were able to pay down existing medical debt by an average of more than $300 per month.

Covered Services

The MCCW provides children and families with approximately three hours per week of respite services and a nurse case manager to assist with coordinating care. A family may choose to hire their own respite worker or elect to receive respite through an agency-based provider.

In addition to services covered under the MCCW, enrolled children have access to services covered through the traditional Medicaid program. These services are typically known as Medicaid State Plan benefits and cover things like inpatient and

outpatient hospitalization, physician services, pharmacy benefits and medical equipment and supplies. The Medicaid State Plan benefit also allows Medicaid to act as a third-party payer to cover the costs of coinsurance and copayments associated with private insurance coverage.

Although the majority of children had private insurance coverage, at the time of the initial survey, 44 percent of families still reported they had forgone or delayed necessary treatment for their child because of costly out of pocket expenses. Access to Medicaid State Plan benefits provides significant assistance to families in these situations. After six months of MCCW participation, only 6 percent of families reported foregoing or delaying a child's necessary treatment due to cost.

MCCW Expenditures

The original appropriation for the pilot program authorized by House Bill 199 (2015) was $3,216,000 in General Fund. An additional $1,000,000 in General Fund was appropriated to the program during the 2016 General Session. These appropriations were designed to fund the program over several years.

During FY 2016, program expenditures totaled $256,324 in General Fund. The actual program expenditures were less than the projections used during the development of House Bill 199 (2015).
Factors that impacted lower than anticipated MCCW appropriation expenditures for the reporting period:

- ***The Department had less than a full year of expenditure data to evaluate***
- ***Utilization patterns may be artificially low and not reflect typical utilization seen in a more mature program***
- ***Respite service utilization could be low due to the need for additional skilled respite staff***
- ***Original estimates were based on Idaho's Katie Beckett program costs for a period prior to the Affordable Care Act's mandatory insurance coverage which meant fewer families likely had private coverage***
- ***The Department did not count State Plan expenditures for the nearly 25 percent of children who were participating in Medicaid prior to enrolling in the MCCW***
- ***Some of the State matching funds were from other government entities rather than the MCCW appropriation***

Conclusions

- Outcome results were positive and showed several key areas of improvement for families.
- MCCW costs were lower than originally projected, but the pilot experience to date is unlikely to fully reflect the utilization that will be seen in a more mature program.
- The program had a positive impact on LEA funding and resulted in $253, 015 of state fund savings for other government entities.

Families' Experiences – *Following are excerpts from letters written by parents of children enrolled in the MCCW. Used with permission of the families.*

"I am writing in regards to how pleased our family is with the MCCW. Our son has spastic quadriplegia and requires 24 hour care. Prior to the MCCW, we were struggling to get his cares met because we could not afford it and my insurance would not cover what he needed…We made decisions on needed treatments throughout the month based on our ability to pay. It was extremely stressful."

"Having 2 children with complex medical needs can be draining and expensive. We are so grateful for the MCCW! It has been a huge help financially to have co-pays covered for therapy visits, doctor visits and medical equipment. Prior to MCCW enrollment, there were times that I would feel guilty about taking my two boys to therapy or specialist visits because of the $40 co-pay per visit and the strain it put on my family… Thank you to all that have provided this help to our family! Life with special needs children can feel overwhelming at times, and anything that helps lift that burden means so much."

"I would like to share my gratitude for the MCCW. I remember the first time getting a prescription filled after getting MCCW coverage. It literally felt like a weight had been lifted off my shoulders. I could not stop smiling when I walked out of the grocery store… Before the MCCW came along I didn't know how I would be able to pay some bills some months… Being able to pay bills, and get supplies that normally aren't covered by our primary insurance is a huge blessing; as is not stressing out about all the many copays. We are very grateful for the help and hope this MCCW continues. We don't know where we would be without it."

Purpose of the Report

The Medicaid Medically Complex Children's Waiver (MCCW) Pilot Report is submitted in response to the following language from House Bill 199 (2015):

> *The department shall annually report, beginning in 2016, to the Legislature's Health and Human Services Interim Committee before November 30 while the waiver is in effect regarding:*
>
> *(a) the number of qualified children served under the program;*
> *(b) the cost of the program; and*
> *(c) the effectiveness of the program.*

Introduction

With the passage of House Bill 199 (2015), the MCCW program was created to provide services to children with disabilities and complex medical conditions. The Department of Health (Department), in collaboration with multiple stakeholders, designed the MCCW Pilot Program. The State submitted the MCCW application to the Centers for Medicare and Medicaid Services (CMS) on June 30, 2015. CMS approved the MCCW with an October 1, 2015 effective date. Within the Department, the MCCW is operated by the Division of Medicaid and Health Financing.

Waiver Development and Implementation

House Bill 199 (2015) provided specific direction on various aspects of program development. This section describes how the Department followed the legislative requirements and implemented the pilot program.

Convene a Public Process

House Bill 199 (2015) directed the Department to convene a public process and submit a Medicaid waiver for CMS approval by July 1, 2015. In April 2015, the Department assembled the MCCW Development Workgroup (Workgroup). The Workgroup was comprised of multiple stakeholders with expertise in caring for medically complex children. Participants included: parents of children with medical complexity, providers of pediatric specialty care services, and professionals from the Department, both from Medicaid and the Bureau of Children with Special Health Care Needs. The Workgroup completed a series of meetings in which a variety of program elements were developed including: defining program eligibility requirements, developing the program application and policies for program admission, defining allowable services including limitations and estimated utilization, and developing provider qualifications and program administration requirements. The Workgroup produced a draft waiver document and the Department disseminated the draft for a 30-day public comment period. The Department created the MCCW webpage where the public was able to view and provide feedback on the draft. The Department also developed a listserv that allowed interested persons to sign up to receive updates about the waiver. In addition, the Department shared the draft document with several other community stakeholders including the Utah Indian Health Advisory Board and Medicaid's Medical Care Advisory Committee.

Develop Eligibility Criteria

House Bill 199 (2015) directed the Department to develop eligibility criteria for program participation. The eligibility criteria that was developed requires children to have a level of medical complexity based on a combination of conditions that involve multiple organ systems, require use of multiple specialty physicians, require high utilization of medical therapies and treatments, and need frequent medical intervention and device-based supports. A child must also have a level of disability determined by the State Medical Review Board or the Social Security Administration.

To be eligible for the program a child must meet three out of the four following criteria:

A. Involvement of 3 or more specialty physicians (in addition to the child's primary care physician)
B. Prolonged dependence (more than 3 months) on device-based supports to compensate for inadequate organ or system function. This includes tracheostomy dependence, use of non-invasive ventilation, oxygen, suctioning, cough assist or CPT treatments, shunts, pumps or monitors.

C. High utilization and prolonged dependence (more than 3 months) on medical therapies, treatments or subspecialty services. This area includes use of central lines, catheters, colostomies, incontinence products, tube feedings, therapies, medications, and mobility-related deficits.
D. Frequent need for medical intervention or consultation. This includes hospital stays, outpatient procedures, Emergency room visits and physician visits or consultations.

To determine if a child met the medical complexity requirements for program participation, the Department implemented a two-part application process: Families were required to 1) complete the MCCW application. The application required families to respond to detailed questions about their child's clinical conditions, and 2) submit written medical documentation from the child's physician. The Department's clinical reviewers used the written medical documentation to substantiate the MCCW application responses provided by the family.

Manage Program Admission through Open Enrollment Periods

House Bill 199 (2015) directed the Department to manage program admission through open enrollment periods. Use of an open enrollment process allowed the Department to fill openings without needing to maintain a waiting list for applicants who exceed the number of available openings.

The Department used a variety of methods to publicize the commencement of open enrollment periods including issuing press releases, posting flyers in Spanish and English in pediatrician offices, sending listserv emails, posting announcements on the MCCW webpage, and working with known advocates and stakeholders to disseminate information to their respective groups.

Table 1 - Enrollment Status from Open Application Periods

Status	October 2015	May 2016
Enrolled	187	154
Denied - Late or Incomplete	17	11
Denied - Level of Care	39	13
Denied - Low Score	18	22
Denied - Other	5	2
Deceased	3	1

Two open enrollment periods have been held since the program's implementation, resulting in 472 applications:

- October 2015 – Total Number of Applicants - 269
- May 2016 – Total Number of Applicants – 203

From the two open application periods, a total of 341 children have been enrolled in the MCCW.

Seek to Prioritize Program Enrollment Based on Medical Complexity and Needs of the Family

The legislation directed the Department to prioritize entrance into the program based on the child's medical complexity and the needs of the family. In order to prioritize enrollment to those with the greatest need, during the development of the MCCW program application, the Department attributed a score to each segment of the application. Based on verifiable responses on the application, the Department calculated a score for each child and ranked the applications based on highest score. The maximum score of the application is 100 points. Although a total of 100 points is available, the Department would not expect to see an individual child with a score of 100 points. The reason is that the available scored elements capture a full array of medical complexities and treatments. It would be highly unlikely that a single child would experience every possible medical complexity and treatment identified in the application.

Sally is an example of a child with a score of 50. She is a 3 year old girl with the following needs:

- **Tracheostomy that requires frequent suctioning to keep her airway clear, requires continuous oxygen with monitoring, and a cough assist to maintain lung compliance.**
- **Is fed and takes 5 daily medications through a g-tube.**
- **Is immobile, deaf or blind and had 10 inpatient hospital stays, 8 Emergency room and 20 physician visits last year.**

Bobby is an example of a child with a score of 30. He is a 1 year old boy with the following needs:

- **Requires daily oxygen use with monitors and frequent suctioning to keep his airway clear.**
- **Is fed through a g-tube.**
- **Is blind or deaf and requires frequent Occupational and Physical therapy.**
- **Is immobile and had 5 visits to the emergency room last year.**

For example, the Department reviewed several applications in which a highly complex child was residing in an acute care hospital or receiving intensive skilled care in a specialty nursing facility at the time of application. These children's scores were typically in the 50-60 range.

Children served on the MCCW have a wide variety of complex diagnoses that include diverse genetic conditions, Cerebral Palsy, Muscular Dystrophy, etc.

Susan is an example of a child with a score of 15. She is a 13 year old girl with the following needs:

- **Has very limited mobility and requires a walker and a wheelchair.**
- **Requires frequent Occupational and Physical Therapy.**
- **Had 4 visits to the emergency room last year.**
- **Requires substantial physical assistance with activities of daily living and takes 5 medications daily.**

Applicants selected for enrollment through the open application process must also receive financial eligibility and disability determinations from the Department of Workforce Services (DWS). Any applicants who do not have a current disability determination from the Social Security Administration must have a disability determination from the Department's Medical Review Board.

Table 2 - Enrollment Details from Open Application Periods

Enrollment Period	Total Enrolled	Avg. Score	Avg. Age
October 2015	187	31.89	6.42
May 2016	154	29.73	5.15
TOTAL	**341**	**30.95**	**5.87**

Both enrollment periods allowed qualified applicants with an MCCW Application score of 14 or more to be enrolled. Table 2 summarizes enrollment details.

Demographics

Since its inception, 341 children have been enrolled in the MCCW statewide. Detailed demographic information of children served is found in Table 3 below.

Table 3 - Demographics of Children Receiving Waiver Services

Waiver Enrollee Information	Children Served	
	Oct 2015	May 2016
Gender		
Females	83	67
Males	104	87
Medicaid Status		
Existing Medicaid Participants Prior to MCCW Enrollment	45	39
New Medicaid Participants due to MCCW Enrollment	142	115
Age at Time of Admission		
Ages 0-5	103	100
Ages 6-12	61	45
Ages 13-18	23	9
Children Served by Region		
Salt Lake County	72	69
Utah County	39	24
Davis County	19	15
Weber County	10	14
Northwestern Utah (Box Elder, Cache, Tooele and Rich Counties)	22	10
Northeastern Utah (Morgan, Summit, Wasatch, Duchesne, Daggett and Uintah Counties)	10	12
Southern Utah (Beaver, Carbon, Emery, Grand, Garfield, Juab, Kane, Millard, Sanpete, Sevier, San Juan, Piute, Wayne, Iron and Washington Counties)	15	10
Disenrolled from the Waiver by Reason		
Moved out of State	4	0
Aged out – Turned 19	0	0
Death	4	2
Miscellaneous Information		
Households with Multiple Children Enrolled	7	9

Services

Waiver Services

Respite Services- Provided through either Medicaid Enrolled Agencies or Self-Directed Services

Respite Services are available to give relief to the child's primary caregivers. Families use an average of 3 hours of Respite per week. Services may be delivered by either a traditional, agency-based provider or the family may hire their own employees through the self-directed services method. Depending on the clinical needs of the child, Respite Services may be need to be provided by a registered nurse (Skilled Respite) or the service may be provided by another employee who is not a licensed clinician (Routine Respite.) The registered nurse (RN) case manager determines the needed skill level of the Respite Services provider during the initial care plan meeting with the child's family. The rate paid for Routine Respite is the same as the rate offered in the Autism Waiver, $19.08 per hour (Agency-based) or $11.96 (Self-Directed.) The Skilled Respite rate is $44.36 (Agency-based) or $27.08 (Self-Directed) per hour, which is the same rate paid in the Technology Dependent Waiver.

Financial Management Service

Financial Management Services is offered in support of the self-directed services delivery option. Services rendered under this definition include those that facilitate the employment of Respite Service providers by the child's parent including:

a) Provider qualification verification;

b) Employer-related activities including federal, state, and local tax withholding/payments;

c) Medicaid claims processing and reimbursement distribution, and

d) Providing monthly accounting and expense reports to the family.

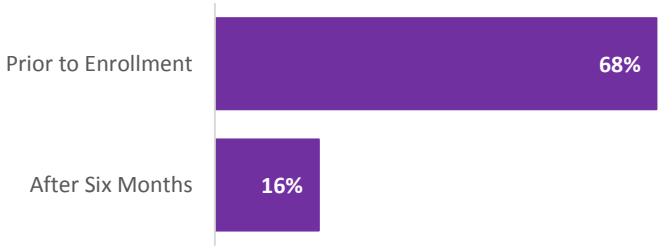
The rate paid for this service is the same as the *Financial Management Services* rate offered in the Community Supports Waiver, $51.67 per month.

Case Management

When developing a home and community based services (HCBS) waiver, states can decide whether Case Management will be provided as a direct waiver service or as an administrative function. Because the program was developed as a pilot program and due to the need for highly skilled RNs with pediatric experience, the Department opted to perform case management as an administrative function. In addition to ensuring consistency in enrollment and care plan development, by using Department nursing staff to provide Case Management, the Department is eligible to draw down enhanced federal funding at a 75/25 match rate.

RN case managers serve an important role in helping families coordinate care across delivery systems and payers. The MCCW RN case managers offer an important service not only by helping the family access necessary services for their child, but also by helping them navigate an often confusing and difficult health care delivery system. The impact of Case Management services is expressed in survey results in Figure 1. The number of families who reported needing additional help to coordinate care during an initial parent survey dropped sharply when the families were surveyed again after being enrolled in the program for six months.

Figure 1 - Families who need additional help coordinating care



State Plan Services

In addition to services covered under the MCCW, enrolled children have access to services covered through the traditional Medicaid program. These services are typically known as Medicaid State Plan benefits and cover things like inpatient and outpatient hospitalization, physician services, pharmacy benefits and medical equipment and supplies. The Medicaid

State Plan benefit also allows Medicaid to act as a third-party payer to cover costs of coinsurance and copayments associated with the child's private insurance coverage.

Although the majority of children had private insurance coverage, at the time of the initial survey, 44 percent of families still reported they had forgone or delayed necessary treatment for their child because of costly out of pocket expenses. Access to Medicaid State Plan benefits provides significant assistance to families in these situations. After six months of MCCW participation, only 6 percent of families reported foregoing or delaying a child's necessary treatment due to cost.

State Plan Services Delivery Method – Fee for Services or Accountable Care Organization

Medicaid members living along the Wasatch Front and in many counties throughout the State receive their State Plan benefits through an Accountable Care Organization (ACO) contracted with the Department. Medicaid members who reside in the remaining counties, or those who are newly enrolled in Medicaid and haven't yet selected an ACO receive their State Plan benefits on a fee for service basis from providers that contract directly with Medicaid. Because the Department did not have utilization history to use as the basis to determine what the monthly capitation payment amount for this cohort of children would be, the Department decided that during the pilot period, it would pay MCCW enrollees' State Plan medical benefits on a fee for service basis.

Program Expenditures

The original appropriation for the pilot program authorized by House Bill 199 (2015) was $3,216,000 in General Fund. An additional $1,000,000 in General Fund was appropriated to the program during the 2016 General Session. These appropriations were designed to fund the program over several years. During FY 2016, program expenditures totaled $256,324 in General Fund. The actual program expenditures were less than the projections used during the development of House Bill 199 (2015).

Factors that impacted lower than anticipated MCCW appropriation expenditures for the reporting period:

- ***The Department had less than a full year of expenditure data to evaluate –*** CMS authorized the MCCW to begin on October 1, 2015 so FY 2016 does not reflect 12 months of expenditures.
- ***Utilization patterns may be artificially low and not reflect typical utilization seen in a more mature program –*** Since the program was not authorized until October 2015, available utilization and claims data is limited to the period when families were just starting to receive services. With a new program, it usually takes several months for typical utilization to be observed.
- ***Respite service utilization could be low due to the need for additional skilled respite staff–*** Due to statewide nursing shortages, lack of available nursing staff to provide Skilled Respite make it appear that utilization is less than it would have been if qualified staff where available to meet the demand.
- ***Original estimates were based on Idaho's Katie Beckett program costs for a period prior to the Affordable Care Act's mandatory insurance coverage which meant fewer families likely had private coverage –*** Approximately 82 percent of MCCW enrollees have private health insurance coverage that is the primary payer. As a result, the MCCW is likely paying for less costly copayments and coinsurance than would have been incurred if Medicaid was the primary payer.
- ***The Department did not count State Plan expenditures for the nearly 25 percent of children who were participating in Medicaid prior to enrolling in the MCCW –*** Because the State Plan benefits for these children were already being paid through Medicaid's general caseload costs, the Department did not attribute $318,900 in General Fund for their State Plan costs to the MCCW appropriation.
- ***Some of the State matching funds were from other government entities rather than the MCCW appropriation –*** The availability of the MCCW allowed other governmental entities, such as school districts (local education authorities (LEAs)), to maximize their state dollars to draw down federal Medicaid funds for required services. For example, for children enrolled in MCCW, because school-based services are reimbursable by Medicaid, the LEAs only needed to pay the state matching funds for these services rather than shoulder the entire cost. The state portion of the funding for these services is provided by LEAs and does not result in expenditures to the MCCW general fund appropriation. $107,200 in state funds came from LEAs rather than the MCCW appropriation. Replacing state funds with federal Medicaid funds resulted in $253,015 in overall state fund savings for these entities.

Waiver Costs

The Department attributed waiver costs for all enrolled children to the MCCW appropriation. Waiver costs include: Respite, Financial Management and Case Management Services. Waiver services are limited to services authorized on a person-centered care plan. Typically participants are limited to 3 hours per week of respite services. Table 4 below shows the breakdown of waiver costs for FY 2016.

Table 4 - FY 2016 Waiver Service Expenditures			
	MCCW General Fund Appropriation	**Federal Funds**	**Total Funds**
Respite and FMS	$19,006.36	$44,859.10	$63,865.46
Case Management	$70,059.40	$184,018.64	$254,078.04
Total Waiver Services	**$89,065.76**	**$228,877.74**	**$317,943.50**

State Plan Costs – Paid by MCCW Appropriation (New Medicaid Enrollees)

The Department attributed State Plan costs to the MCCW appropriation for all children who were newly eligible for Medicaid when they enrolled in MCCW. For most of these services Medicaid is the secondary payer and so typically only pays for copayments or coinsurance. This substantially reduces the costs carried by Medicaid for these services. State Plan costs were attributed to the MCCW appropriation when the Department was responsible for paying the state portion of these services.

State Plan Costs – Paid by Other State Funding Sources

In addition to MCCW services, participants often receive services through other programs that are funded by state, local or other government entities. For example, as mandated under the Individuals with Disabilities Education Act (IDEA), many of these children receive extensive services during the school day. For children who are not Medicaid eligible, the local education authority (LEA), is responsible to pay the entire cost of the services that a medically complex child receives while at school. For children enrolled in Medicaid, because school-based services are reimbursable by Medicaid, the LEAs only need to pay the state matching funds for these services rather than shoulder the entire cost. The state portion of the funding for these services is provided by LEAs and does not result in expenditures to the MCCW general fund appropriation. Replacing state funds with federal Medicaid funds resulted in $253,015 in overall state fund savings. State fund costs paid by entities other than the Department were accounted for separately and were not attributed to the MCCW appropriation.

Table 5 below outlines the costs for State Plan services by category and indicates whether the state match was attributed to the MCCW appropriation or to another governmental entity.

Table 5 - FY 2016 State Plan Service Expenditures Attributed to the MCCW Appropriation and Other State Sources				
	MCCW General Fund Appropriation	**State Match from Other Sources**	**Federal Funds**	**Total Funds**
School Based Services	$0.00	$107,200.11	$253,015.33	$360,215.44
Pharmacy	$95,370.90	$0.00	$225,095.85	$320,466.75
Medical Supplies	$20,999.39	$0.00	$49,563.07	$70,562.46
Physician Services	$6,798.20	$0.00	$16,045.20	$22,843.40
Other Services	$44,090.05	$58,116.66	$236,229.81	$343,436.52
Total Costs	**$167,258.54**	**$165,316.77**	**$779,949.26**	**$1,117,524.57**

State Plan Costs – Attributed to Medicaid's General Caseload (Those participating in Medicaid prior to MCCW enrollment)
For the nearly 25 percent of children who were participating in Medicaid prior to enrolling in the MCCW, because the Department was already paying for State Plan services for these children, the Department attributed these State Plan costs to Medicaid's general caseload expenditures and not to the MCCW appropriation. See *FY 2016 State Plan Expenditures – Attributed to Medicaid's General Caseload Funding* in Table 6 below.

Table 6 - FY 2016 State Plan Expenditures – Attributed to Medicaid's General Caseload Funding

	State Funds	Federal Funds	Total Funds
Outpatient Hospital Services	$70,855.65	$167,234.56	$238,090.21
Inpatient Hospital Services	$69,550.69	$164,154.59	$233,705.28
Home Health Services	$31,881.22	$75,246.52	$107,127.74
Pharmacy	$30,427.63	$71,815.75	$102,243.38
Other Services	$116,183.60	$274,218.29	$390,401.89
Total Costs	**$318,898.79**	**$752,669.71**	**$1,071,568.50**

Total State Costs from All Funding Sources (MCCW Appropriation, Medicaid Caseload Appropriation and Other Governmental Entities)
Although state funds came from multiple funding sources, to demonstrate all the state fund costs attributed to MCCW participants, the Department compiled the data on all Medicaid expenditures for program enrollees. See *FY 2016 Expenditures by Funding Source* in Table 7 below.

Table 7 - FY 2016 Expenditures by Funding Source

	State Funds	Federal Funds	Total Funds
MCCW Appropriation	**$256,324.30**	**$623,643.87**	**$879,968.17**
State Plan Services	$167,258.54	$394,766.13	$562,024.67
Waiver Services	$89,065.76	$228,877.74	$317,943.50
Medicaid Caseload	**$318,898.79**	**$752,669.71**	**$1,071,568.50**
Other Sources	**$165,316.77**	**$390,183.13**	**$555,499.90**
Total Costs	**$740,539.86**	**$1,766,496.71**	**$2,507,036.57**

MCCW Appropriation Total Costs (Waiver and State Plan)
To show costs attributed to the MCCW appropriation, the Department compiled the data on only those services attributed to the MCCW appropriation. Table 8 also shows the remaining balance of the original House Bill 199 (2015) appropriation.

Table 8 - FY 2016 MCCW Expenditures and Appropriation

	General Fund
State Plan Services	$167,258.54
Waiver Services	$89,065.76
Total FY 2016 Expenditures	**$256,324.30**
FY 2016 Appropriation Amount	**$3,216,000.00**
FY 2017 Appropriation Amount	**$1,000,000.00**
Remaining Balance	**$3,959,675.70**

The MCCW appropriation is intended to be spent over the course of the pilot program.

Funding Conclusions

- State Fund expenditures from all funding sources (MCCW appropriation, Medicaid general caseload funding and other State entities' funding) came much closer to approximating the cost projections used during House Bill 199 (2015) development. (Number of months with expenditures during pilot period FY 2016 = 8, FY 2017 = 12 and FY 2018=12 equals 32 months. $3,216,000/32 months = $100,500 per month x 8 Months = $804,000 estimated compared with $740,540 actual.
- Although not contemplated during the MCCW pilot program development, the program has had a positive impact on LEA funding. Once children were enrolled in the MCCW, the LEAs only needed to pay the state matching funds ($107,200) for school based services rather than shoulder the entire cost ($360,215). With the availability of federal Medicaid funding, this program resulted in **$253,015 of state fund savings.**
- With the addition of 154 more children from the May 2016 open enrollment period, and the expected increases in service utilization of a more mature program, expenditures are expected to be significantly higher in FY 2017 than FY 2016. The Department will have considerably more program experience and stable utilization data to report in the MCCW annual report for FY 2017.
- Even with more stable utilization, it is unlikely the entire remaining appropriation will be used by the end of FY 2018. Therefore, policymakers could consider the following program options:
    - Continue the pilot for enrolled members beyond FY 2018
    - Conduct one or more additional open enrollment periods
    - Modify the waiver benefit package to either increase the amount of approved respite services or add services to the benefit package
    - Remove unspent funding from the program at the end of FY 2018 and end the MCCW waiver

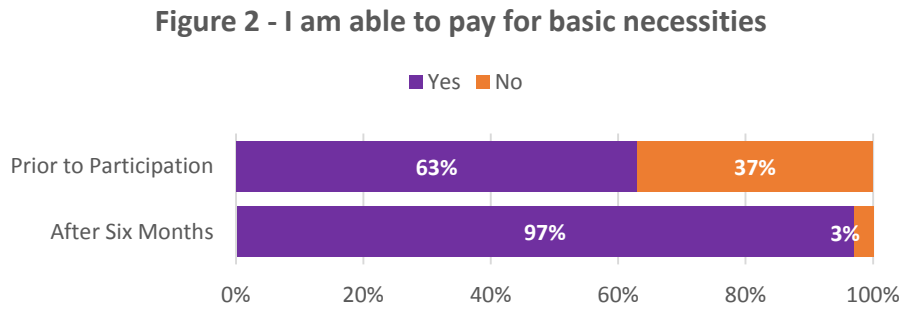
Family Impact

The MCCW was established to address an array of significant issues that families caring for children with complex medical care needs must confront. Families caring for medically complex children frequently experience substantial financial hardships due to the high cost of medical treatments, equipment, and supplies. Financial issues also include job loss or reduction of parental income related to the considerable effort involved in caring for a child with complex needs. In addition, families experience pervasive emotional stressors as well as strained relationships with a spouse or other children in the family.

To evaluate program effectiveness in addressing these issues, the Department conducted a baseline survey with each family upon the child's enrollment in the MCCW and a follow-up survey after the child had been participating in the MCCW for six months. The surveys assessed three areas of impact to the family: financial and employment challenges, health care coverage, and emotional stress.

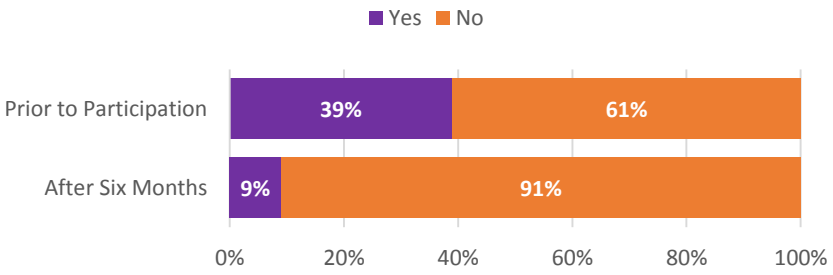
Financial Challenges

This section of the survey evaluated the impact of the child's medical expenses on the family's ability to pay for basic necessities and the medical debt incurred by the family.



The initial parent survey showed that 37 percent of program participants had difficulty or inability to pay for basic necessities such as food, heat or housing due to their child's medical expenses. Only 3.4 percent of families in the follow-up survey reported an inability to pay for basic necessities. These results indicate that the MCCW has allowed participating families to reallocate their resources from medical expenses to basic needs.

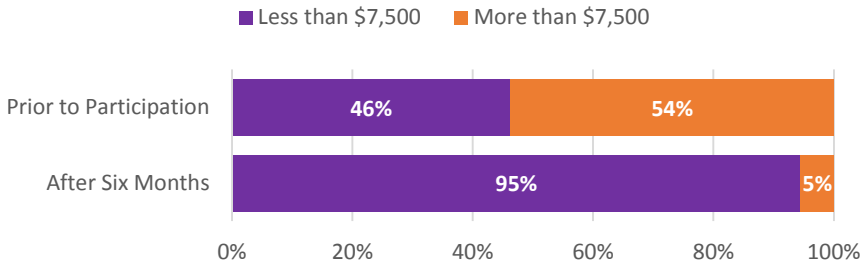
Figure 3 - I have incurred medical debt



The survey indicated that nearly 40 percent of families had incurred medical debt prior to coming into the program. After six months of participation, less than 10 percent reported incurring additional medical debt. Families who reported incurring medical debt incurred an average of almost $11,000 over the year prior to enrollment. This average dropped to about $3,500 after six months of enrollment. In the follow up survey respondents were also asked about whether or not they were able to reduce medical debt they had previously incurred. A quarter of respondents indicated that they were able to reduce debt following program enrollment. Debt was reduced by an average of $2,200.

Out of pocket medical expenses also present significant financial challenges for families. Although the majority of children had private insurance coverage, at the time of the initial survey, about 54 percent of families still reported they had incurred over $7,500 in annual out of pocket medical expenses to care for their child. After 6 months of program participation, only 5 percent of families reported anticipating spending more than $7,500 per year on their child's out of pocket medical expenses.

Figure 4 - Estimated Annual Out-of-Pocket Medical Expenses



In addition to increased medical debt, families with medically complex children are typically more likely to declare bankruptcy than the general population.

Utah's personal bankruptcy rate for 2015 was roughly 4 filings per 1,000 individuals. The initial survey showed a rate nearly 18 times higher among respondents (70 filings per 1,000 individuals). While coverage through the MCCW program does not cover all expenses related to caring for the medically complex child, it significantly reduces the family's medical liability and therefore their incurred medical debt.

Employment Challenges

The survey also focused on the family's ability to seek and maintain gainful employment. In addition to hardships related to paying for the child's medical costs, families face employment challenges such as job loss or reduction of parental income related to the considerable effort involved in caring for a child with complex needs. Prior to program enrollment, 66 percent of respondents indicated that a parent or caretaker had to either reduce hours worked or leave employment in order to care for their medically complex child. After six months of program enrollment 35 percent of respondents reported that they were able to increase hours worked, or re-enter the workforce.

Impact on Families with Children Participating in Medicaid prior to MCCW Enrollment

About 75 percent of the children served in the MCCW are those who were determined eligible at the time of MCCW enrollment. These children were determined eligible by using the HCBS financial eligibility criteria which only evaluates the child's income and assets. This type of eligibility determination does not consider the family's income and assets.

For the 25 percent of children, who were participating in Medicaid prior to MCCW enrollment, the child qualified under the standard financial eligibility rules which consider the family's income when determining eligibility. It is likely that

many of these families were on the Medicaid Spend-down program and would qualify during months when their child's medical expenses were high, and not qualify in other months when medical expenses were lower.

The greater flexibility allowed in HCBS waiver eligibility resulted in significant improvements in income and employment measures for these families. The initial survey found that approximately 19 percent of these families reported forgoing a raise or promotion in order to maintain Medicaid eligibility for their medically complex child.

The survey completed after six months of MCCW enrollment found that the additional flexibility provided by the HCBS waiver eligibility process allowed some families to increase their income without fear of losing the child's Medicaid eligibility. As a result, 20 percent of previously Medicaid eligible families reported an average annual increase in earnings of $7,317.

Health Care Coverage

In both the initial and follow up surveys, roughly 82 percent of families reported that their child had primary insurance coverage (in addition to Medicaid). This indicates that coverage through the MCCW is not a substitute for private insurance, but rather a supplement to other health insurance coverage. For families covered by private insurance, Medicaid typically only reimburses for copayment or coinsurance or services not covered by the family's private insurance.

Although the majority of children had private insurance coverage, at the time of the initial survey, 44 percent of families still reported they had forgone or delayed necessary treatment for their child because of costly out of pocket expenses. Access to Medicaid State Plan benefits provides significant assistance to families in these situations. After six months of MCCW participation, only 6 percent of families reported foregoing or delaying a child's necessary treatment due to cost.

Emotional Stress

In addition to the financial and employment challenges faced by families with medically complex children, families, and in particular caregivers, face a daunting amount of emotional stress. Primary caregivers often feel like their lives are out of balance and may feel like they are neglecting themselves, their relationships with family and friends, and may even feel despondent or depressed – often referred to as caregiver burnout. This section of the initial and follow up surveys focused on indicators of caregiver burnout and the impact of program enrollment on those indicators.

Parents and caregivers were asked to rate their ability to cope with the demands of raising a child with special health care needs. Figure 6 depicts the change in respondents' reported ability to cope with the demands of caring for a medically complex child before and after enrollment in the program.

Families were also asked to rate their level of agreement with several statements that might be indicative of caregiver burnout. For these questions, a rating of disagree or strongly disagree is positive rather than negative. Figures 7-9 indicate the change in some of the responses between program enrollment and six months of program participation. In each case, there is a definite decrease in the number of families who are experiencing symptoms of caregiver burnout.

Figure 6 - How are families coping with caring for their child?

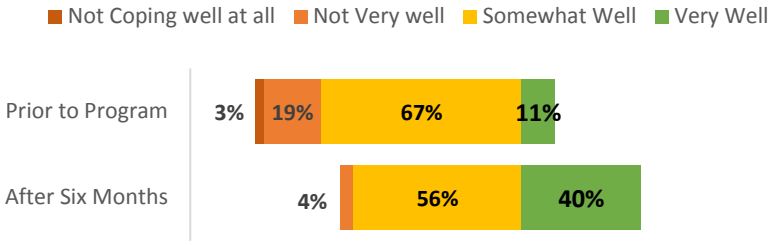
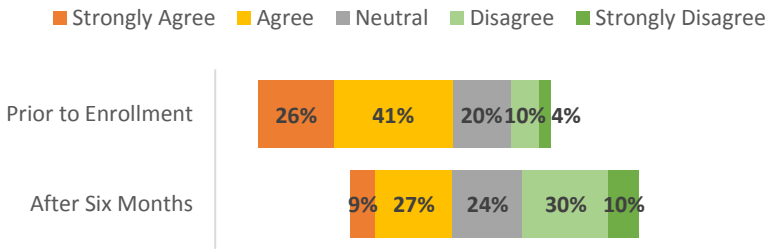


Figure 7 - I feel completely overwhelmed



The number of caregivers who indicated feeling completely overwhelmed went from 67 percent prior to program enrollment to 36 percent after six months of participation. In addition, the number of respondents who indicated feeling lonely or isolated decreased from 56 percent to 26 percent. These results indicate that the respite benefit provided as a part of the program is helping to provide the relief that primary caregivers need in order to continue to care for their medically complex children at home.

Figure 8 - I feel lonely or isolated

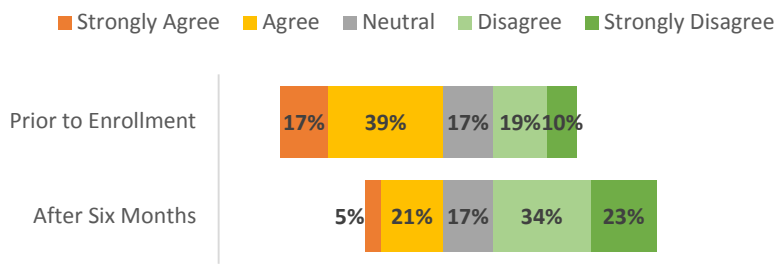
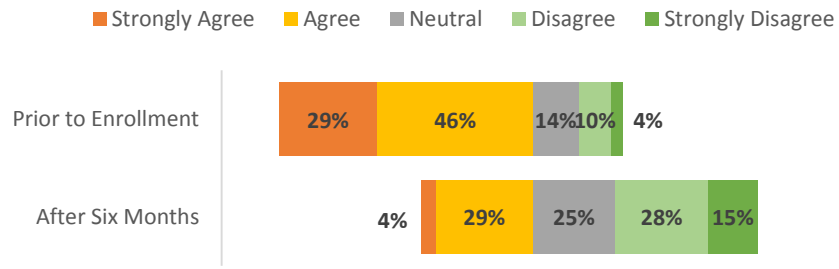


Figure 9 - I feel I am neglecting important relationships



Parents and caregivers often feel like they are neglecting important family relationships by spending a considerable amount of time caring for their medically complex child. Not only is this an indication of potential caregiver burnout, but it is also an indication of increased strain on the continuity of family and other external supports for both the child and the caregiver. Initial surveys showed 75 percent of caregivers felt they were neglecting important relationships in order to care for their medically complex child. Following enrollment and participation in the program, only 33 percent of caregivers described feeling that way.

One parent described the impact of Respite Services provided through the MCCW this way:

> *"I have really tried to use the respite care available through the MCCW to focus on my other kids. It has made me feel less stressed and taken some of the burden off all of us. It has really made a difference in our home and made caring for my son with special needs more manageable."*

Survey data confirms this parent's statement. Respondents indicated that they were able to spend more time outside the home after enrollment in the program, leading to decreased feelings of isolation and improved relationships with family and friends. While initial surveys showed only half of caregivers were able to engage in activities outside the home without the medically complex child, in the follow up survey, 86 percent were able to engage in activities outside the home at least monthly.

Conclusion

The MCCW has successfully provided services to 341 children with complex medical conditions. MCCW costs were lower in FY 2016 than originally projected but part of the difference comes from factors that are likely unique to the program's start up period. MCCW outcome results were positive and showed several key areas of improvement for families. The program has had a positive impact on LEA funding and resulted in $253,015 of state fund savings for other government entities.