Report to the Health and Human Services Interim Committee

Medically Complex Children's Waiver Pilot

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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 576 children statewide. Children were enrolled during three open enrollment periods; October 2015, May 2016 and May 2017. In total, the Department received 837 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, families are also surveyed after six months in the program, and annually thereafter. Survey results are positive and show improvement in several key areas.

Improved Outcomes for Families 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 initial, six-month, and annual surveys, roughly 84 percent of families reported that 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 number of families incurring additional debt dropped by 75 percent and families were able to pay down existing medical debt by an average of more than $1,800 per year.

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, 38 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 7 percent of families reported foregoing or delaying a child's necessary treatment due to cost. This was also true for respondents to the survey after a year in the program. Families reported these expenses were due to services that are not covered under the Medicaid State Plan or the MCCW, such as a home or vehicle modification.

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. Expenditures in FY 2017 were $1,342,400. Factors that impacted MCCW appropriation expenditures for the reporting period:

- ***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 roughly 24 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***
- ***The program had a positive impact on Local Education Agency (LEA) funding and resulted in $714,680 of state fund savings for other government entities.***

Families' Experiences – Following are excerpts from letters written by parents of children enrolled in the MCCW. (Note: these excerpts are used with permission of the families.)

This has been life changing! With MCCW enrollment we have been able to access critical services for our child that we would otherwise never had access to… . We are grateful for this program! We are no longer accumulating debt for exorbitant medical bills, and we no longer worry about getting him the services his needs. Thank you!

Our family has experienced many positive outcomes as a direct result of our child's participation in the MCCW. Since our child's enrollment in the MCCW, we have not had to incur any new debt to pay for his medical expenses. We no longer have to alternate (or go without) providing critical services to him. Respite care has provided us with the opportunity to become more involved in the community, network for our son, occasionally work more hours, or simply have the opportunity to become better parents. All of this means less stress, more help for our child, and improved outcomes for us all!

We have been able to be free of the fear that our daughter's health care costs would bankrupt us. We have been confident that she will be able to get the health care and services she needs. The MCCW Program is an invaluable asset for parents with medically complex children. We are grateful we have been able to participate in the program.

With the MCCW my husband has been able to take promotions at work without fear of us losing Medicaid for our child… . I don't know what we would do without the waiver.

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. The Department assembled the MCCW Development Workgroup (Workgroup). The Workgroup was comprised of multiple stakeholders with expertise in caring for medically complex children. The Workgroup completed a series of meetings in which a variety of program elements were developed. 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.

Table 1 - Enrollment Status from Open Application Periods

Status	Oct-15	May-16	May-17
Enrolled	187	154	235
Denied - Late or Incomplete	17	11	29
Denied - Level of Care	39	13	58
Denied - Low Score	18	22	41
Denied - Other	5	2	2
Deceased	3	1	0

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.

Three open enrollment periods have been held since the program's implementation, resulting in 837 applications:

- October 2015 – Total Number of Applicants - 269
- May 2016 – Total Number of Applicants – 203
- May 2017- Total Number of Applicants- 365

From the three open application periods, a total of 576 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. 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

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.**

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. 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.

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

Table 2 - Enrollment Details from Open Application Periods			
Enrollment Period	Total Enrolled	Avg. Score	Avg. Age
Oct-15	187	31.89	6.42
May-16	154	29.73	5.15
May-17	235	26.08	3.93
TOTAL	576	28.98	5.08

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.**

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.**

Demographics

Since its inception, 576 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	May 2017
Gender			
Females	83	65	104
Males	104	89	131
Medicaid Status			
Existing Medicaid Participants Prior to MCCW Enrollment	45	38	45
New Medicaid Participants due to MCCW Enrollment	142	116	190
Age at Time of Admission			
Ages 0-5	103	100	151
Ages 6-12	61	45	69
Ages 13-18	23	9	15

Children Served by Region			
Salt Lake County	72	69	94
Utah County	39	24	53
Davis County	19	15	21
Weber County	10	14	18
Northwestern Utah (Box Elder, Cache, Tooele and Rich Counties)	22	10	24
Northeastern Utah (Morgan, Summit, Wasatch, Duchesne, Daggett and Uintah Counties)	10	12	10
Southern Utah (Beaver, Carbon, Emery, Grand, Garfield, Juab, Kane, Millard, Sanpete, Sevier, San Juan, Piute, Wayne, Iron and Washington Counties)	15	10	15
Disenrolled from the Waiver by Reason			
Moved out of State	6	4	0
Aged out – Turned 19	0	0	0
Death	5	4	1
Transitioned to DSPD Services	9	2	0
Other	2	4	1
Miscellaneous Information			
Households with Multiple Children Enrolled (Cumulative)	7	9	10

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 $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.

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 was established to match the *Financial Management Services* rate offered in the Community Supports Waiver during state fiscal year 2016, $51.67 per month.

<u>*Case Management*</u>
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.

Figure 1 - Families who need additional help coordinating care

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. Prior to enrollment, 67 percent of families reported needing additional help coordinating care. There was a sharp reduction after 6 months of program participation, and families reported only 20 percent needing additional help coordinating services. After one year, 17 percent of families reported needing additional help coordinating services. After participating for more than one year, 86 percent of parents reported their RN case manager was responsive and supportive of their needs. 87 percent of parents also reported after one year that the RN case manager has an adequate understanding of the child's medical conditions.

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, 38 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 seven percent of families reported foregoing or delaying a child's necessary treatment due to cost. Follow up surveys conducted after a year of program participation were consistent with the six month surveys, showing 93 percent of families were no longer forgoing necessary treatment.

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 through FY 2018. During FY 2017, program expenditures totaled $1,342,400 in General Fund.

Factors that impacted MCCW appropriation expenditures for the reporting period:

- ***The Department had more expenditure data to evaluate –*** CMS authorized the MCCW to begin on October 1, 2015 FY 2016 did not reflect 12 months of expenditures. FY 2017 reflects a full year of utilization for the October 2015 cohort and the 2016 cohort. With the addition of the May 2017 cohort the Department would expect to see an increase in FY 2018.
- ***Respite service utilization could be low due to the need for additional skilled respite staff–*** Due to statewide nursing shortages, a lack of available nursing staff to provide Skilled Respite could cause utilization to be less than it would have been if sufficient 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 84 percent of MCCW enrollees have private health insurance coverage, which serves as 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 $934,203 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. $307,330 in state funds came from LEAs rather than the MCCW appropriation. Replacing state funds with federal Medicaid funds resulted in $714,680 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 2017.

Table 4 - FY 2017 Waiver Service Expenditures

	MCCW General Fund Appropriation	Federal Funds	Total Funds
Respite and FMS	$156,606.95	$364,265.36	$520,872.31
Case Management	$155,308.51	$382,420.94	$537,729.45
Total Waiver Services	**$311,915.46**	**$746,686.30**	**$1,058,601.76**

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 $714,680 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.

For 2017, 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 2017 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	$307,330.86	$714,680.28	$1,022,011.14
Pharmacy	$252,334.52	$0.00	$587,684.68	$840,019.20
Medical Supplies	$138,055.82	$0.00	$321,361.07	$459,416.89
Physician Services	$49,461.97	$0.00	$115,161.66	$164,623.63
Other Services	$590,631.77	$141,476.16	$1,706,369.38	$2,438,477.31
Total Costs	**$1,030,484.08**	**$448,807.02**	**$3,445,257.07**	**$4,924,548.17**

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 2017 State Plan Expenditures – Attributed to Medicaid's General Caseload Funding* in Table 6.

Table 6 - FY 2017 State Plan Expenditures – Attributed to Medicaid's General Caseload Funding			
	State Funds	**Federal Funds**	**Total Funds**
Outpatient Hospital Services	$85,302.12	$199,010.15	$284,312.27
Inpatient Hospital Services	$108,201.31	$251,613.21	$359,814.52
Home Health Services	$216,224.33	$503,418.47	$719,642.80
Pharmacy	$145,564.40	$338,878.12	$484,442.52
Other Services	$550,589.69	$1,282,962.36	$1,833,552.05
Total Costs	**$1,105,881.84**	**$2,575,882.32**	**$3,681,764.16**

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 2017 Expenditures by Funding Source* in Table 7 below.

Table 7 - FY 2017 Expenditures by Funding Source			
	State Funds	**Federal Funds**	**Total Funds**
MCCW Appropriation	**$1,342,399.54**	**$3,147,726.76**	**$4,490,026.30**
State Plan Services	$1,030,484.08	$2,401,040.46	$3,431,424.54
Waiver Services	$311,915.46	$746,686.30	$1,058,601.76
Medicaid Caseload	**$934,202.86**	**$2,176,518.46**	**$3,110,721.32**
Other Sources	**$620,533.06**	**$1,443,691.53**	**$2,064,224.59**
Total Costs	**$2,897,135.46**	**$6,767,936.75**	**$9,664,972.21**

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 - MCCW Expenditures and Appropriation		
	General Fund	
	FY2016	FY2017
State Plan Services	$167,258.54	$1,030,484.08
Waiver Services	$89,065.76	$311,915.46
Total Expenditures	**$256,324.30**	**$1,342,399.54**
FY 2016 Appropriation Amount	**$3,216,000.00**	
FY 2017 Appropriation Amount	**$1,000,000.00**	
Balance Available for FY 2018	**$2,617,276.16**	

Funding Conclusions

- 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 ($307,330) for school based services rather than shoulder the entire cost ($1,022,011). With the availability of federal Medicaid funding, this program resulted in $714,680 **of state fund savings.**
- With the addition of 154 more children from the May 2016 open enrollment period and 235 children from the May 2017 open enrollment period, we have seen the expected increases in service utilization of a more mature program. As expected, the expenditures are significantly higher in FY 2017 than FY 2016. The Department has considerably more program experience and stable utilization data to report in the MCCW annual report for FY 2017.
- Based on current enrollment figures and forecasted utilization, the Department expects to spend a substantial portion, but does not expect to exhaust, the remaining balance of the appropriation in FY 2018. The Department anticipates there will be roughly $500,000 in State General Funds remaining when the pilot expires at the end of FY 2018.

Family Impact

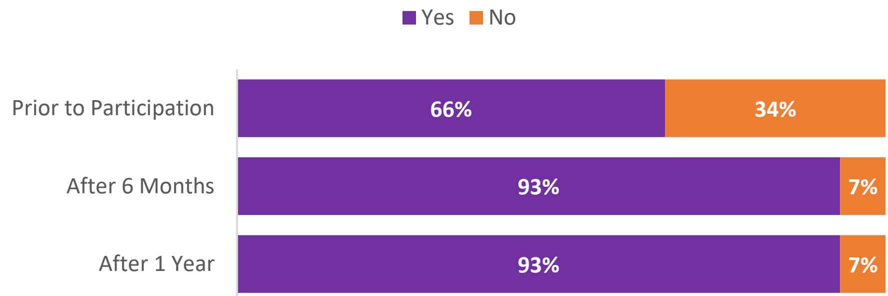
The MCCW was established to address an array of significant issues that families caring for children with complex medical care needs must confront. Families caring for medically complex children frequently experience substantial financial hardships due to the high cost of medical treatments, equipment, 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, a follow-up survey after the child had been participating in the MCCW for six months, and annually thereafter. The surveys assessed four areas of impact to the family: financial and employment challenges, health care coverage, emotional stress and feedback on the performance of MCCW case managers.

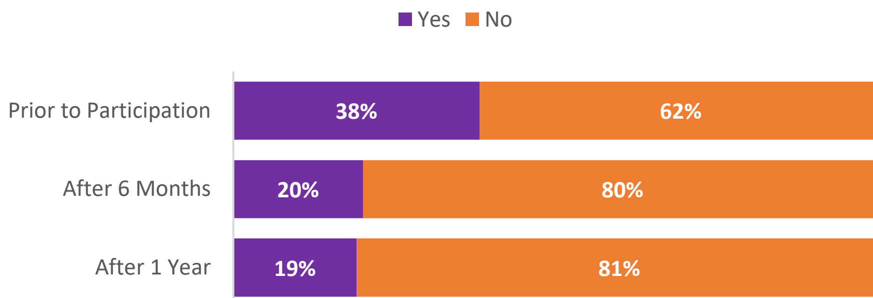
Financial Challenges

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.

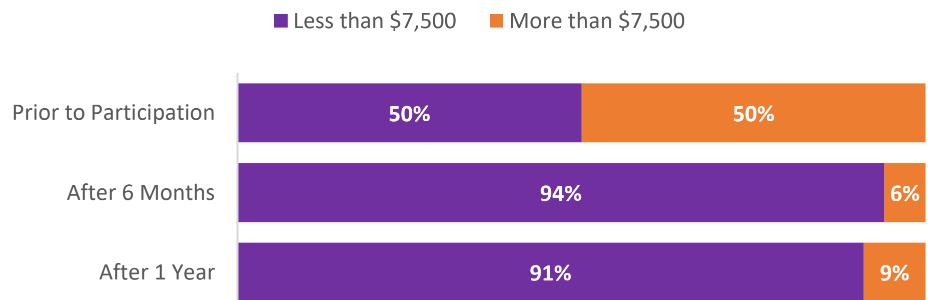
The initial family survey showed 66 percent of respondents were able to pay for basic necessities (roughly one third of respondents indicated they had difficulty or were unable to pay for those necessities). Following six months participation in the program 93 percent of respondents indicated they were able to pay for basic necessities. Surveys conducted one year following the six month survey still showed 93 percent of respondents indicating they were able to pay for basic necessities (see Figure 2).



The survey indicated that nearly 40 percent of families had incurred medical debt prior to coming into the program. After six months of participation, only 20 percent reported incurring additional medical debt. Families who reported incurring medical debt incurred an average of more than $9,000 over the year prior to enrollment, however following enrollment in the program, 20 percent of respondents indicated they were able to reduce debt by an annual average of $1,800.



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 50 percent of families 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 6 percent of families reported anticipating spending more than $7,500 per year on their child's out of pocket medical expenses. While the surveys conducted after more than a year of enrollment showed a slight increase in the percentage of respondents who estimated more out-of-pocket medical expenses, the Department does not believe this difference is statistically significant.



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 in December 2016 was roughly 4 filings per 1,000 individuals. The initial survey showed a rate more than 11 times higher among respondents (45 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 household income related to the considerable effort involved in caring for a child with complex needs. Prior to program enrollment, 71 percent of respondents indicated 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 41 percent of respondents reported they were able to increase hours worked, or re-enter the workforce. Participants who were surveyed a year later showed more than 50 percent 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 families participating in the program. The initial survey found that approximately 20 percent of 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. After six months, 41 percent of previously Medicaid eligible families reported an average annual increase in earnings of more than $2,100. After the one year follow up, 57 percent of previously eligible families reported increased income of more than $2,700.

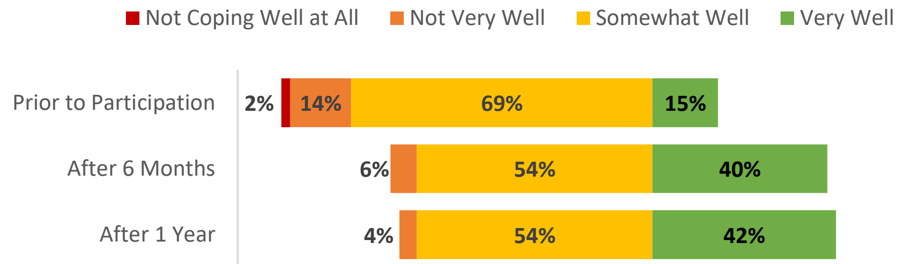
Health Care Coverage

In the initial, six month, and annual follow up surveys, roughly 84 percent of families reported that their child had primary insurance coverage (in addition to Medicaid). This indicates 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.

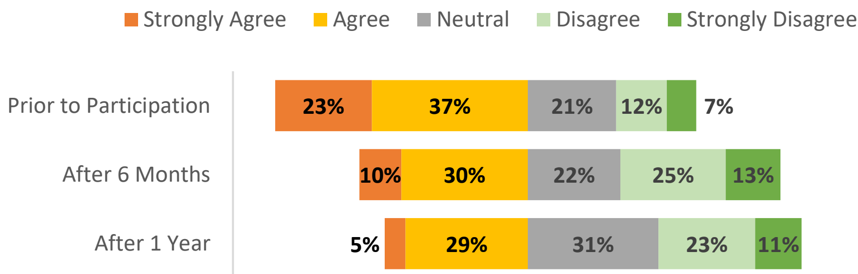
Although the majority of children had private insurance coverage, at the time of the initial survey, 38 percent of families still reported they had forgone or delayed necessary treatment for their child because of costly out of pocket expenses. Access to Medicaid State Plan benefits provides significant assistance to families in these situations. After six months of MCCW participation, only 7 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 5 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 6-8 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. In addition, while the most pronounced decrease in symptoms of caregiver burnout comes during the first six months of program participation, the trend continues as seen in the responses of families who have been participating for more than a year.

The number of caregivers who indicated feeling completely overwhelmed went from 60 percent prior to program enrollment to 40 percent after six months of participation. Only 34 percent of respondents to the annual survey indicated feeling completely overwhelmed.

In addition, the number of respondents who indicated feeling lonely or isolated decreased from 49 percent prior to program participation, to 27 percent at the six month survey, to only 23 percent of respondents to the annual survey. These results indicate the case management and respite benefits provided as a part of the program are helping to provide the relief that primary caregivers need in order to continue to care for their medically complex children at home.

Figure 7 - I feel lonely or isolated

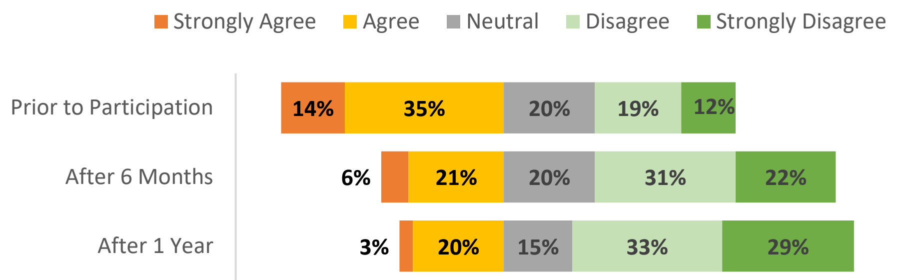
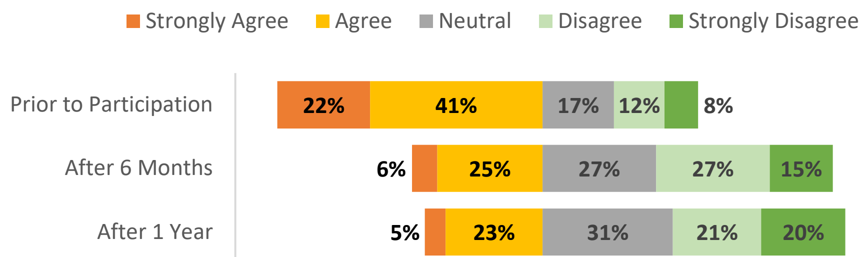


Figure 8 - I feel I am neglecting important relationships



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 63 percent of caregivers felt they were neglecting important relationships in order to care for their medically complex child. Following one year of program participation, only 28 percent of caregivers described feeling that way. As families continued participation in the program the percentage of respondents indicating they were neglecting important relationships continued to decrease reinforcing the trend of improvement over time relative to indicators of caregiver burnout.

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 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. Initial surveys showed more than half of caregivers were consistently able to engage in activities outside the home without the medically complex child. After six months of program participation, 79 percent of parents were able to engage in activities outside the home at least monthly. After a year in the program, 87 percent of parents are able to do so.

Conclusion

- The MCCW has successfully provided services to 576 children with complex medical conditions. 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. Although utilization and expenditures were more predictable throughout FY 2017 as the program matured, expenditures were still less than originally projected. Outcomes continue to be positive and show substantial improvement for families. The program continues to have a positive impact on LEA funding providing a combined $967,965 in federal funds for FY 2016 and FY 2017.
- Because the program was created and funded as a pilot, the MCCW will conclude on June 30, 2018 unless it is reauthorized and additional funding provided. If no additional funding is provided, the Department will initiate a disenrollment plan prior to June 30, 2018 to notify participants and families of program closure.