

Report to the Health and Human Services Interim Committee

Medically Complex Children's Waiver Pilot

Prepared by
Division of Medicaid and Health Financing

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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. During the 2018 General Session, House Bill 100 was passed and the MCCW was converted from a pilot to an ongoing program. The Department convened additional stakeholder meetings and submitted an application to renew the MCCW. CMS approved the renewal effective October 1, 2018.

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 574 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 54 percent and families were able to pay down existing medical debt by an average of more than \$1,000 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 6 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 or more 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 \$1,342,399, and expenditures in FY 2018 were \$1,681,988.

Factors that impacted MCCW appropriation expenditures for the reporting period:

- ❖ ***Respite service utilization could be low due to the need for additional skilled and routine respite staff***
- ❖ ***A high number of program participants (84 percent) continue to have private insurance 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***

Purpose of the Report

The Medicaid Medically Complex Children's Waiver (MCCW) Report is submitted in response to the statutory requirement found in UCA 26-18-410:

- (5) *The department shall annually report 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. During the 2018 General Session, House Bill 100 was passed and the MCCW was converted from a pilot to an ongoing program. The Department convened additional stakeholder meetings and submitted an application to renew the MCCW. CMS approved the renewal effective October 1, 2018. 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 100 (2018) not only instructed the Department to renew the existing waiver, but also to add "additional eligibility criteria" to be evaluated at enrollment and at least annually thereafter. The Department assembled the MCCW Renewal Workgroup (Workgroup). The Workgroup was comprised of multiple stakeholders with expertise in caring for medically complex children, as well as multiple parents of children already enrolled in the program. The Workgroup focused on developing the additional eligibility criteria as well and making other changes based on the lessons learned during the pilot period. The Workgroup produced a draft waiver document and the Department disseminated the draft for a 30-day public comment period. The Department posted the document to the MCCW webpage where the public was able to view and provide feedback on the draft. The Department also notified stakeholders of the changes via the established listserv. 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 three 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.

Changes to Eligibility Criteria effective October 1, 2018

House Bill 100 (2018) directed the Department to continue the waiver as an ongoing program with additional criteria set by the Department. This additional criteria requires periodic reassessment based on the following criteria:

- A. Three or more organ systems affected; AND
- B. Three or more specialty physicians involved in the child’s care or treatment in a comprehensive clinic with different specialty providers; AND
- C. Prolonged dependence (greater than three months) on medical devices or treatments intended to support adequate organ function. The additional criteria required establishment of a minimum medical score. One of the lessons learned during the three year pilot was that a small number of children were being served whose score did not reflect significant medical complexity. The new eligibility criteria requires children served to have a minimum medical score. The minimum medical score will be adjusted based on the current population and allow the Department to prioritize funding to serve the most vulnerable in this population.
- D. Evaluation of Nursing Home Level of Care Criteria: This criteria is evaluated based on the individual needing substantial physical assistance with activities of daily living (ADLs). We evaluate this by assessing the ability of the child to complete age appropriate activities as outlined on the Annual Certification Forms.

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 | 233 |
| Denied - Late or Incomplete | 17 | 11 | 30 |
| Denied - Level of Care | 39 | 13 | 58 |
| Denied - Low Score | 18 | 22 | 41 |
| Denied – Other | 5 | 2 | 3 |
| 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 574 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 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. Based on the direction given in the 2018 General Session, effective October 1, 2018, all participants will be reviewed on an annual basis and must meet a minimum medical score to remain on the waiver. Table 2 summarizes enrollment details.

| Enrollment Period | Total Enrolled | Avg. Score | Avg. Age |
|--------------------------|-----------------------|-------------------|-----------------|
| Oct-15 | 187 | 31.89 | 6.42 |
| May-16 | 154 | 29.73 | 5.15 |
| May-17 | 233 | 26.08 | 3.93 |
| TOTAL | 574 | 28.98 | 5.08 |

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.

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, 574 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 | 102 |
| 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 | 188 |
| Age at Time of Admission | | | |
| Ages 0-5 | 103 | 100 | 151 |
| Ages 6-12 | 61 | 45 | 67 |
| Ages 13-18 | 23 | 9 | 15 |
| Children Served by Region | | | |
| Salt Lake County | 72 | 69 | 92 |
| 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 | 10 | 9 | 7 |
| Aged out – Turned 19 | 3 | 1 | 0 |
| Death | 9 | 7 | 1 |
| Transitioned to DSPD Services | 16 | 9 | 5 |
| Transitioned to Technology Dependent Waiver | 4 | 1 | 0 |
| Other | 2 | 6 | 7 |
| 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 three 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.

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. Prior to enrollment 66 percent of families reported needing additional help coordinating care.

There was a sharp reduction after six months of program participation when families reported only 22 percent needing additional help coordinating services. This appears to have held relatively steady for families since enrollment in the program.

Figure 1 - Families who need additional help coordinating care



After participating for more than two years 98 percent of parents reported their RN case manager was responsive and supportive of their needs. 89 percent of parents also reported after one year that the RN case manager has an adequate understanding of the child's medical conditions, this number increased to 95 percent after two years of program participation. One parent described the impact of Respite Services provided through the MCCW this way:

"Our participation in the MCCW has positively impacted our family... Having a case manager has also provided a starting point for consultation when he has new or changing medical needs..."

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 six 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 survey, showing 93 percent of families were no longer foregoing necessary treatment, the increase after two years of participation is 97 percent.

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. Expenditures in FY 2018 totaled \$1,681,988.31. During the 2018 General Session House Bill 100 appropriated \$2,041,600 in General Fund to implement the program on an on-going basis.

Factors that impacted MCCW appropriation expenditures for the reporting period:

- ***The Department had more expenditure data to evaluate*** – With the addition of the May 2017 cohort the Department expected to see an increase from FY2017 to FY 2018. With more complete utilization data from FY 2017 estimated for expenditures in FY 2018 were closer to estimates than in previous years of the pilot program.
- ***Respite service utilization could be low due to the need for additional skilled and routine 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 were available to meet the demand. In response to lower utilization of routine respite services than anticipated during the pilot period, the Department added licensed Personal Care agencies to the list of qualified providers for routine respite services.

- **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 \$1,080,967.56 in General Fund for their State Plan costs to the MCCW appropriation during FY2018.

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. 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 three hours per week of respite services. Table 4 below shows the breakdown of waiver costs for FY 2018.

| Table 4 - FY 2018 Waiver Service Expenditures | | | |
|--|--|-----------------------|-----------------------|
| | MCCW General Fund Appropriation | Federal Funds | Total Funds |
| Respite and FMS | \$233,378.57 | \$549,941.93 | \$783,320.50 |
| Case Management | \$239,967.65 | \$557,592.70 | \$797,560.35 |
| Total Waiver Services | \$473,346.22 | \$1,107,534.63 | \$1,580,880.85 |

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. State fund costs paid by entities other than the Department were accounted for separately and were not attributed to the MCCW appropriation.

For 2018, 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 2018 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 | \$497,238.52 | \$1,173,372.14 | \$1,670,610.66 |
| Pharmacy | \$317,378.37 | \$0.00 | \$747,085.26 | \$1,064,463.63 |
| Medical Supplies | \$244,600.20 | \$0.00 | \$576,582.15 | \$821,182.35 |
| Physician Services | \$72,088.19 | \$0.00 | \$169,871.34 | \$241,959.53 |
| Other Services | \$574,575.33 | \$403,376.01 | \$2,299,167.25 | \$3,277,118.59 |
| Total Costs | \$1,208,642.09 | \$900,614.52 | \$4,966,078.15 | \$7,075,334.76 |

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 2018 State Plan Expenditures – Attributed to Medicaid’s General Caseload Funding* in Table 6.

| Table 6 - FY 2018 State Plan Expenditures – Attributed to Medicaid’s General Caseload Funding | | | |
|--|-----------------------|-----------------------|-----------------------|
| | State Funds | Federal Funds | Total Funds |
| Outpatient Hospital Services | \$46,973.24 | \$110,636.23 | \$157,609.47 |
| Inpatient Hospital Services | \$161,206.29 | \$379,729.68 | \$540,935.97 |
| Home Health Services | \$255,086.60 | \$600,489.39 | \$855,575.99 |
| Pharmacy | \$296,972.06 | \$698,590.63 | \$995,562.69 |
| Other Services | \$617,206.54 | \$1,452,230.00 | \$2,069,436.54 |
| Total Costs | \$1,377,444.72 | \$3,241,675.94 | \$4,619,120.66 |

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 2018 Expenditures by Funding Source | | | |
|---|-----------------------|-----------------------|------------------------|
| | State Funds | Federal Funds | Total Funds |
| MCCW Appropriation | \$1,681,988.31 | \$3,954,378.57 | \$5,636,366.88 |
| State Plan Services | \$1,208,642.09 | \$2,846,843.94 | \$4,055,486.03 |
| Waiver Services | \$473,346.22 | \$1,107,534.63 | \$1,580,880.85 |
| Medicaid Caseload | \$1,080,967.56 | \$2,544,115.39 | \$3,625,082.95 |
| Other Sources | \$1,197,091.69 | \$2,816,794.75 | \$4,013,886.44 |
| Total Costs | \$3,960,047.56 | \$9,315,288.71 | \$13,275,336.27 |

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 | FY2018 |
| State Plan Services | \$167,258.54 | \$1,030,484.08 | \$1,208,642.09 |
| Waiver Services | \$89,065.76 | \$311,915.46 | \$473,346.22 |
| Total Expenditures | \$256,324.30 | \$1,342,399.54 | \$1,681,988.31 |
| FY 2016 Appropriation Amount | \$3,216,000.00 | | |
| FY 2017 Appropriation Amount | \$1,000,000.00 | | |
| Remaining Balance | \$935,287.85 | | |

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.

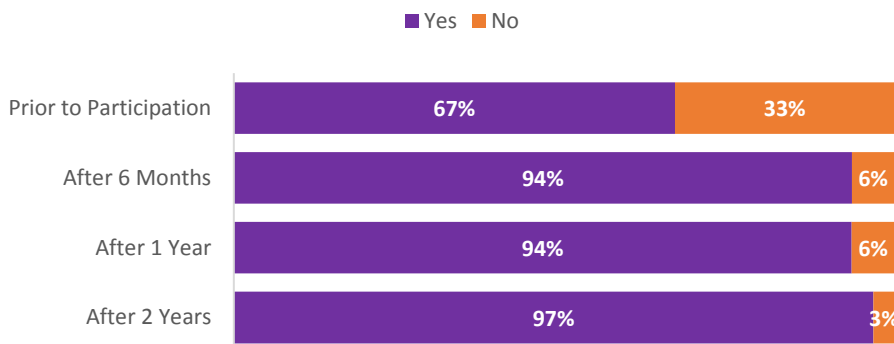
To evaluate program effectiveness in addressing these issues, the Department conducted a baseline survey with each family upon the child's enrollment in the MCCW a follow-up survey after the child had been participating in the MCCW for six months and annually thereafter. The surveys assessed four areas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

employment challenges, health care coverage, emotional stress and feedback on the performance of MCCW case manager.

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.

Figure 2 - I am able to pay for basic necessities

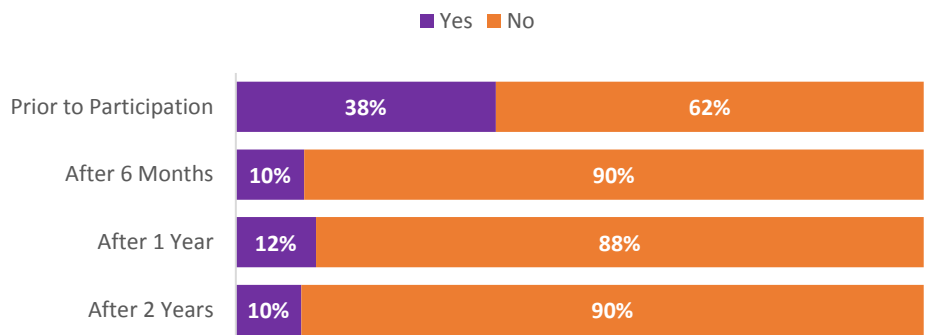


The initial family survey showed 67 percent of respondents were able to pay for basic necessities (roughly one third of respondents indicated that they had difficulty or were unable to pay for those necessities). Following six months participation in the program 94 percent of respondents indicated that they were able to pay for basic necessities. Surveys conducted one year following the six month survey still showed 94 percent of respondents indicating they were able to pay for basic necessities. After two years 97 percent of families were able to pay for basic necessities. (see Figure 2).

percent of families were able to pay for basic necessities. (see Figure 2).

The survey indicated that nearly 38 percent of families had incurred medical debt prior to coming into the program. After six months of participation, only 10 percent reported incurring additional medical debt (see Figure 3). Families who reported incurring medical debt incurred an average of more than \$3,492.44 over the year prior to enrollment, however following enrollment in the program, 88 percent of respondents indicated that they were able to reduce debt by an annual average of \$2,310.88.

Figure 3 - I have incurred medical debt



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 51 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 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 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 39 percent of respondents reported that they were able to increase hours worked, or re-enter the workforce. Participants who were surveyed a year later showed 49 percent were able to increase hours worked, or re-enter the workforce. After participation in the program for two years, 57 percent were able to increase their hours or continue or join 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 survey found that approximately 47 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. At the two year follow up 47 percent report an average increase income of \$12,800.

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 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.

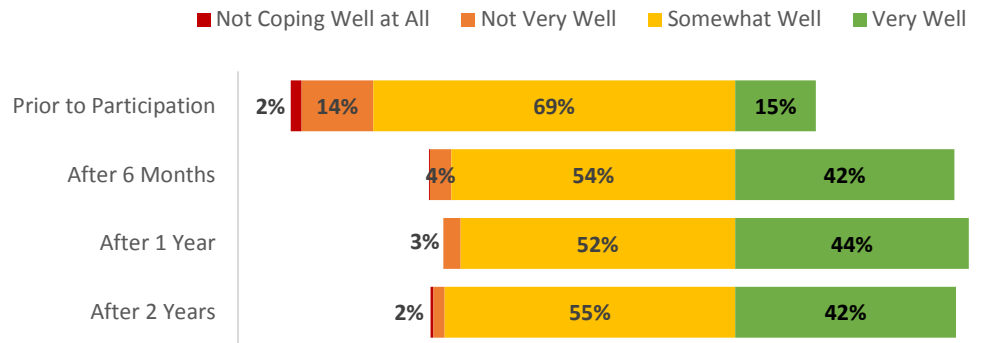
Although the majority of children had private insurance coverage, at the time of the initial survey, 38 percent of families still reported they had forgone or delayed necessary treatment for their child because of costly out of pocket expenses. Access to Medicaid State Plan benefits provides significant 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. The ability to obtain healthcare without delay due to cost continues to improve for families served by the MCCW. After two years of participation only three percent report 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.

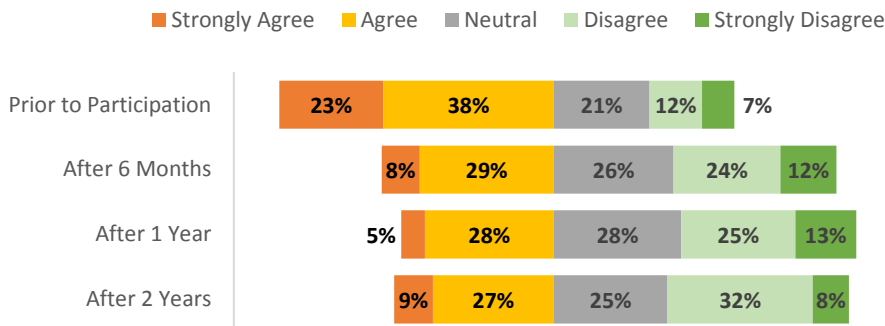
Parents and caregivers were asked to rate their ability to cope with the demands of raising a child with special health care needs. Figure 5 depicts the change in respondents’ reported ability to cope with the demands of caring for a medically complex child before and after enrollment in the program.

Figure 5 - How are families coping with caring for their child?



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, six months, one year and two years 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 - I feel completely overwhelmed



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 61 percent prior to program enrollment to 37 percent after six months of participation. After participation for two years, 33 percent of respondents from 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 23 percent at the six month survey, to only 22 percent of respondents to the annual survey and continues to decrease to 21 percent after two years.

These results indicate that 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

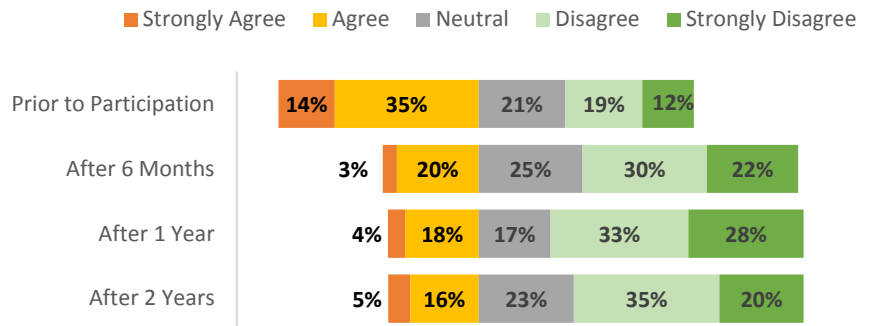
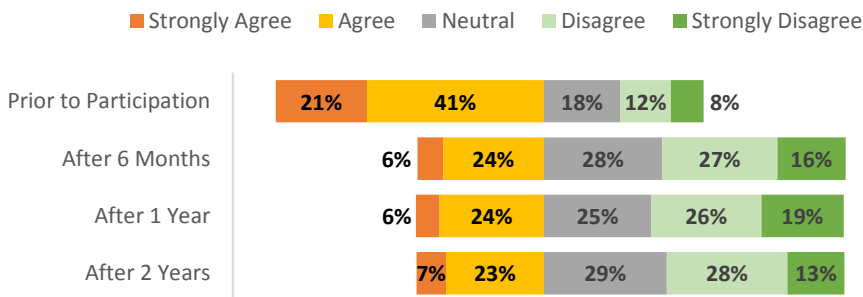


Figure 8 - I feel I am neglecting important relationships



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 62 percent of caregivers felt

they were neglecting important relationships in order to care for their medically complex child. Following six months of program participation, only 30 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.

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

“Respite has been a lifesaver! Getting time away from caring for a total dependent child is so necessary! Medicaid has been such a blessing financially!”

“With the Respite care, it has allowed my wife and I to have more time to do things together. The most significant benefit is that I am very comfortable leaving [my daughter] with the respite nurse because if she were to have a seizure the respite nurse could handle the situation correctly.”

“The respite has helped save our marriage.”

“The respite care has enabled me to take care of needs in the family. My daughter looks forward to playing with her nurse.”

“Having respite so I can have time with my husband and other children has been huge.”

“Respite care has provided opportunities for me to focus on my other children.”

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. While initial surveys showed more than half of caregivers were consistently able to engage in activities outside the home without the medically complex child. In follow up surveys, 79 percent of parents were able to engage in activities outside the home at least monthly after six months of program participation. Responses after two years of participation indicate that 89 percent of parents are able to do so.

Conclusion

The MCCW has successfully provided services to 574 children with complex medical conditions. The program has been successful in its goals of providing support to families with children with disabilities and complex medical conditions through case management and respite services as well as reducing the financial burden of medical expenses related to their child. It is particularly encouraging to see the reported increases in employment for caregivers in the survey. Roughly 25 percent of waiver participants were enrolled in Medicaid prior to waiver participation, but of those families, nearly half reported increases in wages or hours, with an average pay increase of \$12,800 annually. The Department plans to continue collecting information on the impact of the program now that funding is on-going and will continue to use that data to inform future policy decisions.