

Report

Threading the Labyrinth

Why Children in California
with Special Health Care Needs
Endure Delays in Securing the
Medical Equipment and Supplies
They Need

“Most families with a child who has a disability would give anything to *not* need the requested equipment. It’s like adding insult to injury to make it so difficult to obtain any equipment.”— from a Parent Interview

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Executive Summary

Approximately 200,000 children with serious medical conditions receive health coverage through the California Children's Services (CCS) program, whose responsibilities include ensuring that these children are provided with the medically necessary durable medical equipment (DME) and supplies that they require.

Although data are scant, three recent surveys point to frequent long delays in obtaining equipment and supplies. In a 2017 survey of families, 22% of respondents reported waiting a year or more for needed equipment and supplies, and an additional 16% mentioned having cases that were unresolved. Despite such delays, the state has not identified required time frames for getting medically necessary equipment and supplies to children in the CCS program.

Children suffer when medical equipment and supply deliveries are delayed. Parents report that long delays distract them from caring for their children, cause unnecessary developmental delays, and increase physical pain and suffering.

What are the reasons behind these chronic delays, and what can be done to address them?

The author of this report conducted dozens of interviews, including with CCS medical therapists, nurses, physicians, and administrators, vendors, Regional Center and Medi-Cal managed care health plan staff, state officials, advocates, parents, and others. The goal was to understand the administrative obstacles that contribute to delays in obtaining essential supplies and equipment such as wheelchairs, walkers, ventilators, leg braces, and hospital beds.

This report identifies the issues – including payer priority/payer of last resort disputes and CCS internal and vendor-related barriers – that underlie administrative delays. It also highlights promising practices that some counties are engaging in to mitigate delays.

The author offers a set of state- and county-level policy recommendations that address multiple issues underlying the delays. While some of these recommendations may be initiated at the local level, by and large the state should establish standardized requirements, monitor and enforce policies, and provide support to localities as they implement new approaches.

In light of the devastating impact the delays have on children, and in light of the impending implementation of the Whole-Child Model, policymakers should move forward with a sense of urgency to implement these recommendations.

One or more legislative informational hearings would provide an appropriate forum to support information gathering to address how best to move forward to enact these recommendations.

Recommendations

State and/or local policymakers are urged to:

1. Establish a system to track current time frames and, eventually, establish and monitor reasonable required time frames for final delivery;
2. Monitor and enforce memoranda of understanding between local Medi-Cal managed care health plans and county CCS programs;
3. Require that county CCS programs issue payment authorization to vendors as soon as is feasible to address delays related to private health insurer/HMO payer of last resort issues;
4. Require, monitor, and enforce memoranda of understanding addressing payment responsibility between county CCS programs and Regional Centers;
5. Improve internal county CCS program processes;
6. Ensure adequate funding rates to incentivize wider availability of vendors of DME and medical supplies, and to ensure adequate levels of program staff;
7. Create wider availability of alternative sources of DME and medical supplies;
8. Establish a state-level advisory function;
9. Establish county-level coordinating councils; and
10. Support the work of Family Resource Centers and other nonprofit parent-support organizations.

Introduction

One million children and adolescents in California have been identified as having special health care needs¹ and approximately 200,000 of them, ages birth to 21, are actively enrolled and served by the California Children’s Services (CCS) program.²

CCS is a state program run at the county level under state and federal laws, regulations, and through other guidance and communications. Individuals interviewed for this report identified state policies requiring a time-consuming and cumbersome set of hurdles for CCS children in need of medical equipment and supplies including:

- complex decision making regarding who will pay for the item;
- multiple administrative requirements that are not readily facilitated by the programs involved; and
- a shortage of vendors willing/able to fulfill equipment needs timely.

CCS, housed within Children’s Medical Services at the California Department of Health Care Services (DHCS), serves children with certain complex medical conditions. Eligibility in the program is based on medical diagnoses and income.³ The program provides, among other things, durable medical equipment (DME), orthotics, prosthetics, and medical supplies. These products – including wheelchairs, walkers, ventilators, leg braces, hospital beds, and supplies for incontinence, diabetes, breathing, and feeding – may be prescribed by CCS when they are medically necessary for the particular health condition that made the child eligible for the program.

“Parents of children with special health needs do not have spare time like other parents do. Not to mention that calling everyone is extremely frustrating and complicated. The job of resolving interagency billing disputes should not fall in our laps.” – Parent of CCS Child

CCS eligibility encompasses a variety of health conditions, ranging from cancers to spinal cord injuries.^{4,5} However, meeting the program’s eligibility requirements, combined with demonstrated medical need for the CCS-eligible medical condition for equipment and supplies, is no guarantee that the needed equipment and supplies will be made available in a timely manner.

The existence of multiple payers, who each may have some responsibility toward these children, may create barriers resulting in lengthy administrative delays. These delays may be due to prolonged decision making among potential payers regarding which payer should be required to pay for equipment and supplies, and/or to slow-moving intra- and inter-agency administrative processes.

Currently there are no CCS rules in place regarding how long children can be kept waiting to receive medically necessary medical equipment and supplies. Reports from families and health care providers consistently point to lengthy and unnecessary administrative delays being common, and at times, running a year or longer. The impact can be devastating. Parents report that their children

suffer exacerbated health conditions, developmental delays, physical pain and pressure sores, among other detrimental outcomes.

To identify specific administrative problems leading to these delays, the author reviewed the results of a Family Voices of California 2017 survey of families of children with special health care needs (CSHCN), a 2016 survey by the National Health Law Program, and a 2015 survey by the Children's Regional Integrated Service System (CRISS). The author interviewed dozens of CCS medical therapists, nurses, physicians and administrators, as well as vendors, Regional Center and Medi-Cal managed care health plan staff, state officials, advocates, parents, and others. (Please see Appendix A: List of Interviewees).

“I know it will take months and that I will be arguing with [insurance] and CCS and trying to get the vendor to understand what my child needs so an order can be put in. All of that time when I am on the phone, sending emails, going to the vendor site, is time I cannot care for my son.” – Parent of CCS Child

In some respects, this report only scratches the surface, providing an overview of this tangled process. The author describes the labyrinth, identifies the issues that underlie administrative delays at each step, and uncovers promising practices some counties are engaging in to mitigate delays.

The report concludes with a set of state and county-level policy recommendations to address delays in delivery of medically necessary DME and medical supplies.

Family Voices of California Parent Survey

To understand the consumer perspective, the author reviewed the results of a 2017 Family Voices of California survey of parents whose children were served by CCS. Results indicated that these families, already fully engaged in the care of their children, are often strapped with the added responsibility of juggling a complex set of bureaucratic requirements – at times on a daily basis – for months, sometimes even for years, to secure medically necessary equipment and medical supplies to which their children are entitled. Survey results included:

- 22% of respondents reported waiting a year or more for equipment;
- An additional 16% of respondents mentioned having cases that continued to be unresolved at the time of the survey;
- 18% of respondents said that they had experienced delays that meant their child had to stay in the hospital until they received the equipment;
- 86% of families described adverse impacts that delays in DME had on their children including:
 - loss of independence, including being unable to leave home;
 - delays in development;
 - frustration and endangered safety;
 - pressure sores; and
 - physical pain.

Family Voices of California Survey – Full Details

Between February 10 and March 5, 2017, Family Voices of California (FVCA), which works to ensure quality health care for CSHCN, surveyed parents whose children are served by CCS. The survey posed a series of open-ended questions focusing on problems families have accessing DME and medical supplies (See Attachment B: List of Family Voices of California Survey Questions). FVCA and the Lucile Packard Foundation for Children’s Health sent the English-only online survey to their networks.

The experiences of families who reported delays regarding DME then were analyzed. In total, 66 responses were submitted. For the purpose of this analysis, the responses of 49 families who cited delays related to DME were investigated. Seventeen responses were informative but did not fit the inclusion criteria.¹

Among the remaining 49 responses, common themes and distinct highlights were explored. The nature of the survey – open-ended as opposed to multiple-choice questions – allowed respondents to provide rich detail. However, because all questions were open-ended, respondents likely offered what was top-of-mind for them; the fact that something might not have been mentioned in their response does not mean they have not had that experience. Therefore, the following percentages quantifying the qualitative responses are likely conservative.

From the 49 parents whose responses are included in this analysis, the following was found:

- Eighty-six percent (86%) of respondents described adverse impacts that delays in DME had on their children.
 - These range from loss of independence including being unable to leave home, frustration and endangered safety, to delays in development.
 - Of those respondents that described adverse impacts, 38% reported that their child’s condition was exacerbated, development meaningfully delayed, or in one case, the child had more hospitalizations. Some examples of reported adverse impacts:
 - back and arm pain when using a walker that was too small;
 - poor posture for a child who already has airway obstruction and curvature of the spine;
 - a child who needed to sleep on a mattress on the floor, because of the lack of a hospital bed, repeatedly rolled onto the floor and had her feeding tube yanked out and experienced serious acid reflux because pillows did not provide adequate elevation;
 - physical pain while being in a hunched over position during the time period during which she waited for a new wheelchair;
 - lost strength in hands and arms that, due to the child’s condition/inability to regain skills once lost, will be permanent;

Continued

¹ Seven responses were put aside because they appeared to be from medical providers or others, rather than families. Another three were set aside because the respondents discussed concerns that were not delays. Two were set aside because the respondents do not have DME, and an additional five were set aside because the respondents either left most of the survey blank, said “no” or “not applicable” throughout, did not have concerns, or had not experienced a delay.

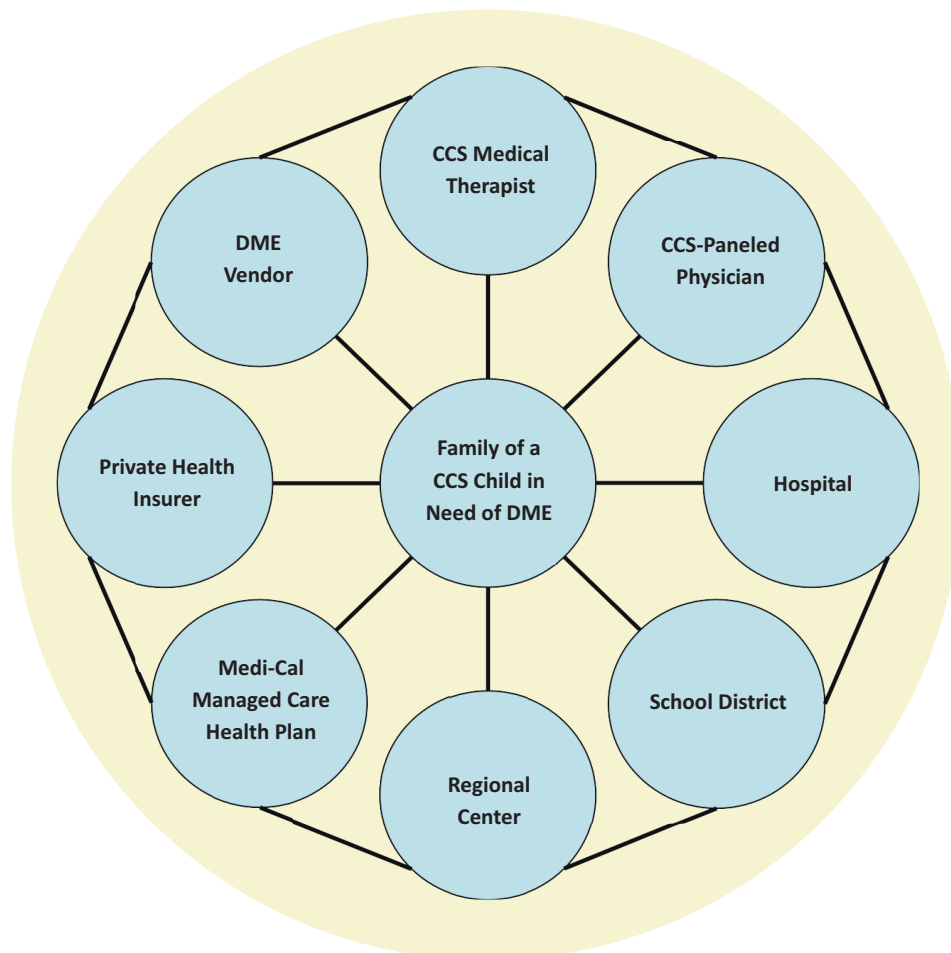
Family Voices of California Survey *Continued*

- pressure sores due to outgrown equipment; and,
 - teen unable to take daily showers while waiting for ill-fitting bathroom equipment to be replaced.
- Notably, over half (53%) of respondents described delays related to issues with payers, and specifically the presence of multiple payers.
- Parents cited a range of challenges that lead to delays:
 - Thirty-seven percent (37%) discussed challenges with vendors, including:
 - vendors not being willing to order specific equipment because the reimbursement rate is too low;
 - vendors taking a long time, losing paperwork, or not providing correct equipment;
 - limited availability for appointments with vendors; and,
 - limited availability of vendors who take CCS Medi-Cal.
- 18% of respondents said that they had experienced delays that meant their child had to stay in the hospital until they received the equipment.
- 22% of respondents reported waiting a year or more for equipment.
- 16% of respondents mentioned having cases that are still unresolved.
- 63% of respondents reported paying out of pocket for something they believed should have been covered by another party, and an additional 8% mentioned that they could not afford to pay out of pocket.
- Respondents gave a range of recommendations for improvement. Numerous respondents recommended working out guidelines for payers, to reduce the delays. Others suggested having point people who work on behalf of families to manage the process. Some described the need for better service by vendors to avoid challenges getting needed equipment.

The Parent of a CCS-Eligible Child in Need of Durable Medical Equipment and Supplies May Be Required to Juggle Multiple Stakeholders

The role that families may be asked to play in procuring DME and medical supplies for their child may vary from county to county and from case to case. In some cases a CCS Medical Therapist or other CCS staff may take the lead in moving the process forward, and in other cases families may be asked to play that role. In either case, it is widely acknowledged that being a “squeaky wheel” can make a difference in obtaining medically necessary DME and medical supplies timely.

For families, the process can be exceedingly time consuming and challenging. The process may be especially difficult for families who are low income, lack education, hold multiple jobs, are not native English speakers, are not health literate, and lack experience moving bureaucracies. Parents may be asked to, among other things: secure a prescription from a CCS-paneled physician specialist; choose and work with a vendor; work to seek payment from private insurers, which may at times include pursuing appeals; and seek coverage from other sources including a Medi-Cal managed care health plan, Regional Center, or school.



An Administrative Labyrinth That Leads to Delays

Multiple administrative barriers – including disputes about who will pay, CCS internal processes, and processes at the vendor level – stand in the way of children receiving the DME and medical supplies they need in a timely manner.

Multiple Layers of Decision Making Regarding Who Will Pay

Administrative delays due to payer priority rules among key California programs that provide DME and medical supplies to children with special health care needs

The phrase “payer of last resort” stands for the concept that certain publicly funded programs, deemed to be “secondary payers,” require families to seek payment for DME and medical supplies from other “primary payer” entities first. Some publicly funded programs will not pay for equipment and supplies unless the family has already exhausted all other payment possibilities. Families of CCS children are required to engage in time-consuming processes that arise among public and private payers seeking to determine who will be the payer of last resort for DME and medical supplies.

“I don’t know about why the delays happen. I feel like a ping pong ball with people pointing at each other.” – Parent of CCS Child

Payer relationship between CCS and Medi-Cal managed care health plans and between CCS and Medi-Cal fee-for-service

Most children who are in the CCS program are Medi-Cal eligible. In the case of CCS children served by Medi-Cal managed care health plans, CCS services are “carved out.”^{6,7} Under this carve-out arrangement, Medi-Cal managed care health plans are responsible for primary care and other services not related to the child’s CCS-eligible condition, while services related to the child’s CCS-eligible condition are authorized and managed by the CCS program.^{8,9}

Standard language in DHCS contracts with Medi-Cal managed care health plans require Medi-Cal managed care health plans and CCS programs to establish memoranda of understanding (MOU) that include agreement that the Medi-Cal managed care health plan will provide medically necessary equipment and supplies when they are not authorized by CCS.¹⁰

In the case of children who are eligible for CCS and for Medi-Cal, when CCS determines that the equipment or medical supplies are medically necessary and associated with the child’s eligible condition, CCS has the power to authorize Medi-Cal fee-for-service payment for the DME or medical supplies.^{11,12}

From Pillar to Post: Dominic's Story

Much to his embarrassment, Dominic started kindergarten in a stroller.

Dominic, now 10 years old, has Duchenne Muscular Dystrophy, three other genetic disorders, and autism.

Despite coverage from private insurance, CCS, Medi-Cal, and the Regional Center, his family could not get him the “push” chair his condition demanded in time for him to start kindergarten. Though it's critical that he not use the muscles required for him to move himself in a wheelchair, his private insurer said the push chair was not medically necessary, and took six months to issue its denial. Finally, CCS paid for the chair. But not in time for kindergarten.

By the time he was eight, Dominic needed a power wheelchair. As is typical of children his age, he wanted some independence, and a power chair would eliminate the need for someone to push him all the time. Once the need for a power chair was established and a visit with the vendor occurred, the CCS Medical Therapy Unit took several weeks to draft the necessary report and send it to the vendor. Then the vendor said, “We're backlogged.” The private insurer took a while to issue its denial. Then the family had to return to CCS to get a new prescription from a physician because the original prescription, written by a nurse practitioner, was deemed unacceptable. Six months later, Dominic got his chair.

But CCS would not pay for a lift to get the wheelchair into the family van. It would only provide a 60-pound metal ramp, which Dominic's mother could not lift. CCS recommended that the family seek coverage from the Regional Center, based on Dominic's qualifying diagnosis of autism. His mother then had to argue with the Regional Center and explain that Duchenne Muscular Dystrophy is closely associated with autism. The Regional Center said that, since the family's van had 75,000 miles on it, they would not cover the cost of the lift. The family explained that they did not have the resources to purchase a new van. The Regional Center required that the family ask CCS to pay for a new van. The family went through that process, was refused, and went back to the Regional Center. Finally, the Regional Center paid for the wheelchair lift. Dominic's mother found it disheartening that many of the staff she dealt with in this process did not seem to understand the rules of the agencies involved.

Sometimes Dominic's family buys necessary DME themselves to avoid the time-consuming and stressful process of going through the health care system to have the products covered. They have done this with shower chairs and the wheelchair lift on the doorway to their home.

Interviewee Reported Delays Due to Payment Disputes Between Medi-Cal Managed Care Health Plans and CCS

- It is reported that in some counties, despite the required presence of an MOU as described above, delays ensue when the Medi-Cal managed care health plan resists payment – sometimes repeatedly – when it disagrees with a CCS determination that the DME or medical supply need is not medically necessary for the child's CCS-eligible condition.¹³

Whole Child Model

In 2016 the governor signed SB 586 into law establishing the Whole-Child Model (WCM)¹⁴, which will integrate the delivery system for CCS fee-for-service with Medi-Cal managed care health plans in 21 California counties.¹⁵ The WCM will be implemented through five Medi-Cal managed care health plans known as County Organized Health Systems (COHS) with Phase 1 implementation beginning in 2018.¹⁶ In WCM counties, vendor authorization requests for durable medical equipment and related supplies will be submitted to the COHS.¹⁷ County CCS programs and COHS will be required to enter into MOU related to ensuring access to services.¹⁸

Payer relationship between CCS and private PPO health insurance

When CCS determines that a child is eligible for the CCS program, and that the need for equipment or supplies is related to the child's CCS-eligible condition and medically necessary, if the child has private preferred provider organization (PPO) health insurance,¹⁹ payment for the item must first be sought from the private health insurer.^{20,21} That is, the private health insurer is the primary payer and CCS is the secondary payer; CCS will be responsible for covering the item in cases when the private insurer says that the benefit being sought is not a covered benefit or payment is denied because the private insurer does not believe the item is medically necessary. In cases where the private insurer says the item is not medically necessary, the family may be asked by CCS to pursue an appeal with the private insurer.

“There seems to be a significant breakdown in who is responsible for providing (paying) for DME when multiple insurance providers are in place. We had a terrible time getting a manual wheelchair and walker because our daughter who is a CCS client also had Medi-Cal and private insurance through my husband's employer. No one knew which party was supposed to be held responsible.” – Parent of CCS Child

Interviewee Reported Delays Due to Payment Determination Processes between Private PPO Health Insurance and CCS

- Private PPO health insurers may take months to provide a decision, even in cases of denials.
- Vendors and families who contact private insurers attempting to expedite the process are often connected to call centers or other staff with no experience regarding DME and medical supply needs of CSHCN. This may result in misunderstandings and repeated and time-consuming requests for additional information.

- Each insurer may require a different set of documentation/justification.
- Private insurers often require lengthy documentation. One county reported that an insurer requested that the insurer's 12-page form be completed; after some time, this insurer finally accepted the CCS Medical Therapy Program's report as documentation.
- Some insurers send their own health care providers out to meet with the child and do their own assessments.
- Some insurers require that the prescription be written in the same month that the insurer's decision is made. Because of delays in the insurer's process, new prescriptions may need to be ordered. In these cases delays may be compounded in geographies where the CCS-paneled physician responsible for writing the prescription only visits the Medical Therapy Unit once a month/occasionally.

Payer relationship between CCS and private HMO coverage

In cases where the child's private insurance coverage is an HMO (as opposed to a PPO plan), CCS may not authorize medically necessary DME or medical supplies until the HMO finds that the DME or medical supplies are not a covered benefit, or until the HMO finds that the DME or medical supplies are not medically necessary. In the latter case, the family may be asked to pursue an appeal through the California Department of Managed Health Care before CCS authorization is pursued. When it is finally determined that the HMO will not pay, then the family may seek CCS authorization for the medical equipment and supplies.²²

Interviewee Reported Delays Due to Payment Determination Processes between Private HMOs and CCS

- Delays similar to those above happen in cases of HMO coverage.
- Since CCS authorization may not be determined until an HMO denial is finalized, the child must wait for this authorization determination to be completed following the HMO denial, before the vendor can be notified that medically necessary DME or medical supplies have been approved, thus further contributing to delays.

Payer Relationship between CCS and Local Education Agencies/Special Education Local Plan Areas

In cases where a child is served by both CCS and a Local Education Agency/Special Education Local Plan Area (LEA/SELPA),²³ a state-level interagency agreement between DHCS and the California Department of Education, Special Education Division, requires the "... uninterrupted delivery of special education services and medically necessary therapy services as identified in the individualized education program or the individualized family services plan when conducted through the LEA/SELPA and coordinated with county California Children's Services."²⁴

DME that is predominantly for school use, including equipment that the child's Individual Education Program team finds necessary for the child to benefit educationally from his/her instructional program, is the responsibility of the LEA.²⁵ CCS funds may be expended only for DME that is medically necessary for the CCS-eligible condition.

If CCS fails to pay, the LEA is required to provide or pay for services to the child in a timely manner and then claim reimbursement for the DME from CCS. The state requires that the LEA and CCS develop a MOU that includes procedures for reimbursement for DME provided or paid for by the LEA.²⁶ In cases where educational need for DME overlaps with the medically necessary need for DME for a CCS-eligible condition, the LEA and CCS may each be responsible for a portion of the costs.²⁷

Payer relationship between CCS and Regional Centers

Twenty-one private nonprofit Regional Centers around the state, under contract with the state Department of Developmental Services, provide certain DME and medical supplies for eligible children with developmental disabilities, without regard to income level.^{28,29} The equipment need must be determined to be medically necessary for the developmental disability that makes the child eligible for Regional Center services. Regional Centers vary in regard to the equipment/supplies they will cover.

Regional Centers are “payers of last resort,”³⁰ that is, Regional Center-eligible children/families are expected to exhaust all other public and private payer sources including CCS, Medi-Cal, special education, and private insurance before Regional Center payment may be provided.

Interviewee Reported Delays Due to Payment Disputes Between Regional Centers and CCS

- Some Regional Centers inquire, sometimes multiple times, about whether CCS will pay for certain DME for children who are both CCS and Regional Center eligible. Interviewees reported that this happens despite the fact that the DME being inquired about is equipment that is never covered by CCS.³¹

Each CCS Internal Administrative Step and Vendor Process Holds Opportunities for Delay

CCS and vendor local administrative processes

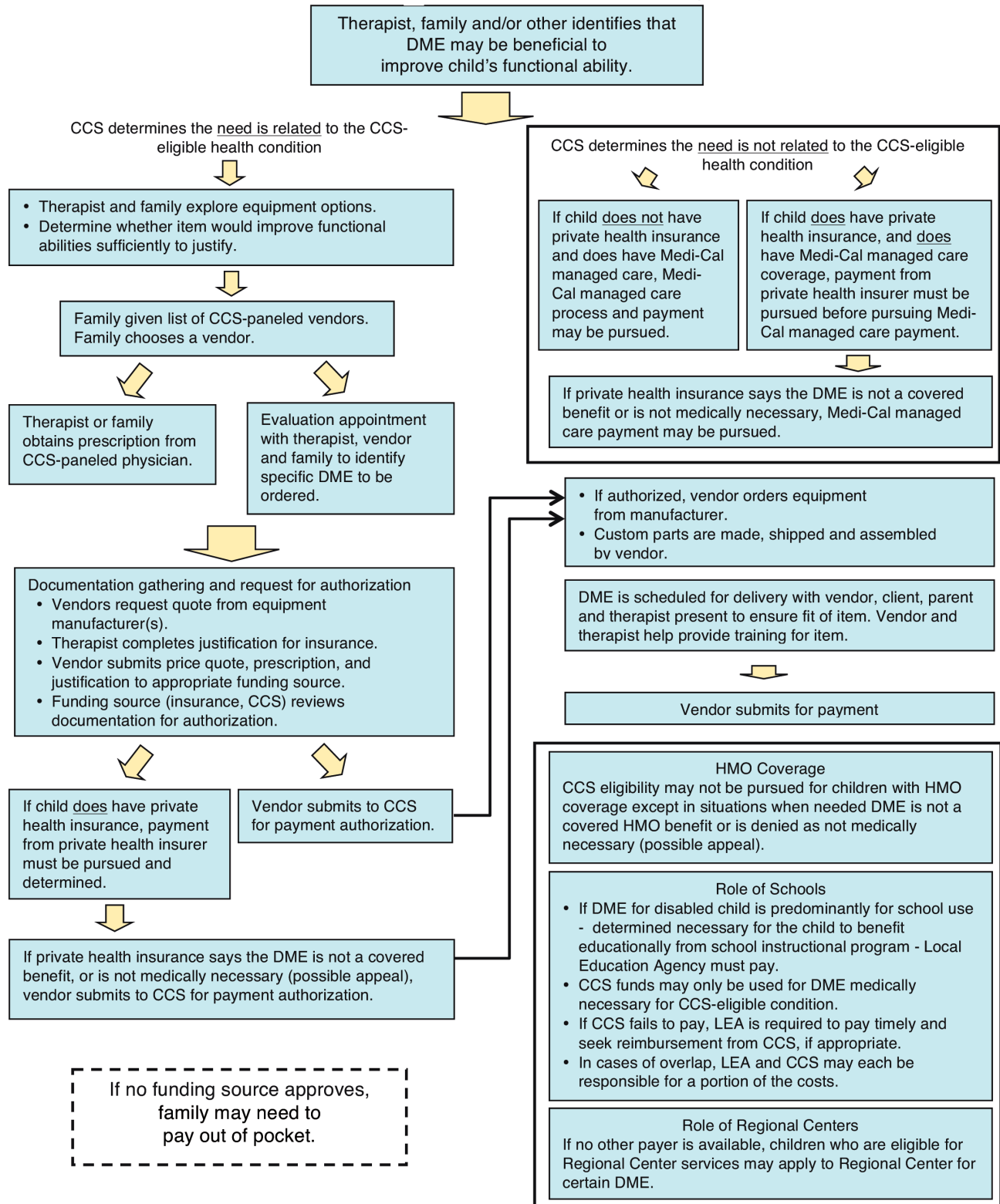
“When the ball is handed off between so many players, it only takes one defective link in the chain to cause a major delay.” – CCS County Staff

In addition to the delays related to payer responsibility issues, delays arise related to CCS internal administrative processes and vendor processes. While many CCS administrative processes vary from county to county and from case to case, the following provides an outline, in general terms, of how the process for obtaining DME and medical supplies commonly proceeds.

- The need for DME or medical supplies may be identified by a CCS medical therapist in the CCS Medical Therapy Program³² and/or by the child's family. The need also may be identified by the child's CCS-paneled physician, a non-CCS physician, the child's caregiver, school, or by others.
- For the process of obtaining DME to move forward, the child's CCS financial eligibility must be up to date and an up-to-date CCS annual assessment must be included in the child's chart.³³

- The CCS medical therapist and the child’s family may explore DME and medical supply options. In the case of medical supplies a CCS registered nurse works with the family to identify medically necessary medical supplies. (See Appendix C: Medi-Cal List of Durable Medical Equipment, Orthotics, Prosthetics, and Medical Supplies).
- The medical therapist may develop a justification for the DME or medical supplies.
- A CCS-paneled physician, approved to treat the child’s CCS-eligible medical condition for which DME or medical supplies is requested, must determine that the equipment is medically necessary for the child’s CCS-eligible condition and write a prescription for the DME.
- DME or medical supplies approved for CCS/Medi-Cal payment may be complex equipment customized to meet the specifications of children with highly specialized pediatric equipment needs. Creating and maintaining this equipment can require a high level of technical design expertise. CCS will provide the family with a list of CCS approved-paneled vendors from which to choose a vendor who will eventually supply the child’s equipment.
- DME vendor technicians may work with CCS medical therapists, families, and children at initial visits to identify together the best equipment for a child’s particular physical characteristics, physical needs, lifestyle, and activities.
- Designing and building this equipment may require the vendor to identify multiple funding codes, order parts from manufacturers around the globe, and finalize a quote for approval by the payer (see payer of last resort related processes page 16). If the payer is to be CCS, the vendor submits a Service Authorization Request (SAR) to CCS.
- Once the authorization for payment is made and the equipment delivered, the vendor, medical therapist, and family may meet to ensure that the equipment is well fitted to the child’s body and needs. Other equipment provided by vendors to CCS children may be more routine, lower cost, “off-the-shelf” products.
- Upon delivery of equipment, the vendor may seek the authorized payment.

Process for CCS-Eligible Children to Obtain Durable Medical Equipment



Interviewee Reported Delays Due to CCS Internal Administrative Processes

**“In some cases, it seems like once one thing goes wrong, everything goes wrong.”
– CCS County Staff**

- The child may not have an up-to-date CCS eligibility and/or Medi-Cal eligibility determination.
- The child may not have an up-to-date annual CCS assessment in their chart.
- The family may attempt to move forward with a prescription that was written by a provider who is not a CCS-paneled physician treating the CCS-eligible condition for which the child needs DME or medical supplies, for example, a prescription from a primary care provider or from another specialist.
- It may be the case that the CCS-paneled physician responsible for writing the prescription only comes to the Medical Therapy Unit once a month. Some vendors will not deliver equipment until the prescription is in the vendor’s hands.
- When CCS SAR forms are completed by CCS manually, sometimes errors including typos, wrong codes, or wrong quantities are entered on the form. Vendors are required to return these mistakes to CCS to be corrected. In some localities it is reported that CCS may take months to return the corrected form to the vendor; some vendors will not deliver equipment until the authorization form is corrected and finalized.
- It may be the case that there are not experienced CCS staff people who hold responsibility for tracking the provision of DME and medical supplies and ensuring timeliness.
- The person responsible for moving the process forward to the next step may be someone who works in multiple CCS locations and can only process the necessary paperwork on the days that he/she is in the location where the particular child is served.
- In situations where the CCS staff person responsible for signing off on the authorization for DME and medical supplies is not highly familiar with DME and medical supply specifications, he/she may undertake a time-consuming process requiring additional information be gathered before authorization is granted.
- Because of the complexity of the process, new, untrained, part-time staff, or low staffing levels can easily lead to delays.

“We can’t make the vendor do anything. We are afraid that if we are too demanding, we might scare the few remaining vendors away.” – CCS County Staff

Interviewee Reported Delays Due to Vendor Administrative Processes

- Interviewees frequently mentioned that low Medi-Cal fee-for-service payment rates to vendors, i.e. those payments authorized by CCS, have led to: difficulty in finding vendors willing to accept these payments; lack of competition among vendors; vendors unwilling to provide or rent certain equipment; and slow/poor customer service from some vendors.
- In rural communities fewer and fewer vendors are available who accept Medi-Cal payment.

- In one high-population, high-cost-of-living county, poor access to vendors was said to be associated with vendors being unable to afford the cost of doing business in that county. Some vendors are spread thin covering several counties and may be able to visit a CCS Medical Therapy Unit only once a month. This can easily mean that it may take a month or two to coordinate schedules for an initial appointment with the family member and medical therapist to identify specific equipment needs. Scheduling delays also arise for final appointments to be sure the equipment is well fitted for the child.
- Sometimes, when a CCS authorization is in place, CCS staff may attempt to persuade a vendor to move forward and prepare the equipment, despite the lack of a final decision regarding who will pay for the equipment. However, some vendors will not order equipment – particularly in the case of expensive equipment – until payment decisions have been resolved between private insurers and CCS. These payer of last resort processes can be lengthy and may include multiple potential private payers as well as appeals. (See discussion of payer of last resort beginning page 10).
- Long delays are reported in securing non-custom, low-cost items such as tub transfer benches, helmets, grab bars, and bath chairs. This situation was also reported to sometimes be the case for repairs and batteries. Months-long waits have been experienced in the process of receiving a quote for a repair or a new battery.
- There is an unwillingness among some vendors to provide short-term rentals³⁴ such as wheelchairs for someone who, for example, is going home after a hospital stay. Interviewees in one county described that the only vendor they could find willing to rent a wheelchair required a family to agree to drive 200 miles to return the rented wheelchair when their child was finished using it after a couple of months.
- Families have had to wait multiple weeks for a single-code quote from a vendor.
- Delays are sometimes caused by what were perceived to be unnecessary back-and-forth processes/human errors because of wrong codes.
- At the final fitting it may become clear that the wrong part has been ordered and the equipment is unusable until steps are taken to correct that.
- When delays are lengthy, it is not unusual for the child to have undergone a growth spurt, or for his/her body to otherwise have changed between the time of the original evaluation and the final delivery, resulting in new equipment that needs to be modified in order to fit the changes in the child's body.

Hospital Discharge Delays

Interviewees reported that it was common to be given inadequate advance notice by hospitals of upcoming discharges of CCS children who are in need of DME or medical supplies. They reported that discharge notices of only three days, or sometimes even less, were not uncommon; short notices were reported even in cases of children who had been hospitalized for months. Sometimes a vendor is able to provide “loaner” equipment to bridge the gap, but sometimes equipment needs are complex and may need to be customized and so cannot be readily available with short notice.

The problems presented by such short notice of discharge may be compounded by a lack of vendors willing to take CCS payment, as well as cumbersome payment authorization processes.

These problems sometimes result in a child needing to stay in the hospital longer than would have been necessary had equipment needs been met more timely. Eighteen percent of families whose responses were analyzed in the Family Voices of California survey (see page 7 for survey details) reported that they had experienced delays that meant that their child had to stay in the hospital for additional time, until they received necessary equipment.

When one California hospital identified discharge delays occurring when CSHCN experienced barriers to obtaining DME and medical supplies timely, the hospital created a “Delay Tracker.” Then, based on what they learned about these delays, they created a “Discharge Assistance Fund” to serve as a “bridge to discharge.” The hospital drafted a letter of agreement with their vendor, asking the vendor to please dispense the equipment when it is requested and letting the vendor know that, if a potential payer, e.g. CCS, Medi-Cal managed care, or private insurance, does not pay, the hospital will pay. This Discharge Assistance Fund has since been used to pay for, among other things, wheelchairs and walkers for children who are otherwise ready for discharge, thus eliminating a barrier to timely hospital discharge.

Independence Gained and Lost: Jim's Story

Jim is seven years old. He has severe osteogenesis imperfecta, a bone disorder, and other complications. While his head is the normal size for a seven year-old, the rest of his body is the size of a typical one year-old. He is 30 inches tall and weighs 20 pounds. His health coverage comes through CCS and Medi-Cal.

Jim is a bright boy, who was able to enjoy some independence and exert some control over his life through the use of a custom power wheelchair. But after three years the chair's battery went dead. His father, a health care professional, got CCS approval for a replacement. It took almost three months to get the battery replaced, during which time Jim had to get around in a stroller or be carried around.

Initially, CCS took several weeks to approve the request for a new battery. Upon receiving CCS approval for the new battery, the vendor then sent a request back to CCS asking CCS to create a labor order, a document required for the vendor to deliver/install the new battery. It took three weeks for CCS to approve this labor order.

During the three months they waited for the battery, Jim's father contacted the vendor and CCS multiple times. The vendor told him the order was overlooked, they were busy, and they were short staffed. Eventually Jim got his battery, but now his father is concerned that his son may lose his independence for months again if, for example, something as small as a bolt gets broken on his wheelchair.

Compounding the problem, more than two years ago the family got a prescription from CCS for a modified commode. Jim has no trunk control, has very weak head control, recurring compression fractures when in sitting position, and requires special handling when being transferred to avoid fractures. Using a bedpan/fracture pan is problematic because the angle/tilting of the pelvis and positioning required can cause injury or fractures. Jim also has issues stooling while lying in a supine position without a commode, so he must wear diapers, which affects his self-esteem.

Two years after the initial approval, CCS tells Jim's father that they are still looking for a vendor to fill this commode order.

Children's Regional Integrated Service System (CRISS) Survey

From April through June 2015, the Children's Regional Integrated Service System (CRISS), which aims to promote seamless service delivery and coordination of care for CCS children, conducted a survey that focused on the topic of DME and medical supplies needs following hospitalizations of CCS children.

CRISS surveyed CCS programs, hospital representatives and family support organizations on access to DME and medical supplies. (See Appendix D: List of Children's Regional Integrated Service System (CRISS) Durable Medical Equipment Access Survey Questions). Seventy-nine responded, including 61 CCS staff from throughout the 27 Northern California-county CRISS region; 10 family organization representatives or parents of CSHCN; and eight hospital or health care organization staff.

The results of the survey identify access to DME and medical supplies as a problem, with many vendors having left the market, and families and hospitals often being required to cover the cost of DME and medical supplies themselves. CRISS reported the following survey findings:

- 56% of respondents reported experiencing delayed hospital discharge due to lack of access to DME or medical supplies. Many respondents reported difficulty finding vendors willing to take CCS payment, including one who said that the closest vendor willing to work with CCS was 150 miles away.
- 39% of respondents said that they have observed hospitals paying for DME or medical supplies to discharge children when no vendors are available.
- Five hospital representatives responded to a question asking whether their hospital is paying for DME or medical supplies, saying that costs range between \$35,000 up to greater than \$100,000 per year.
- 36% of respondents said they have observed families paying for DME or medical supplies when vendors are not available.
- 72% of respondents reported that they have seen some or many families experience significant hardship due to the cost of DME or medical supplies.
- Respondents in general reported a lack of vendors willing to accept Medi-Cal/CCS and that some vendors are leaving the market. Low rates and difficulty in submitting CCS claims were cited as reasons for vendors refusing to accept CCS. Several respondents reported issues accessing specific supplies because vendors are unwilling to provide them, including broviac supplies, oxygen supplies, pediatric tubing, hearing aids, wheelchairs, lift slings, diabetic supplies, pediatric specialty walkers, and crutches.

Varying County Level Efforts to Mitigate Delays

Some county CCS programs make efforts to mitigate delays

Fortunately, a number of county CCS programs have identified approaches to speed up the process of securing medically necessary DME and medical supplies including: encouraging vendors to expedite DME and medical supply orders even while waiting for decisions regarding who will be the final payer; assigning CCS staff to serve as “DME Coordinators” to work with families, vendors, payers, and CCS therapists, physicians, and administrators to move the process forward at each step; creating a CCS internal system meant to track each step of the administrative process to identify and, eventually address, common delays; and establishing relationships and educational opportunities among the various agencies involved to facilitate communication and the timely delivery of equipment and supplies.

CCS is a California state program that is run at the county level. Some state policies and procedures for the CCS program are laid out in “Numbered Letters” from DHCS addressed to all county CCS programs. Some policies and procedures are governed by state statutes, the California Code of Regulations Title 22, Medi-Cal Provider Manuals, and other written sources.

In addition, DHCS holds periodic conference calls with local CCS leaders to communicate new policies and procedures and to discuss existing ones. Interviewees report that a considerable amount of new policy guidance for CCS county programs is never put in writing by the state. This lack of written clarification, coupled with CCS staff frustration with seemingly unnecessary delays, may underlie the extent to which there is variability from county to county throughout the state. Interviewees referred to this situation saying that local programs are governed to an extent by “phantom rules,” “folklore,” and “legend.”

“... things become rules that aren’t actually rules. Even though there is no basis for it, it becomes part of the bureaucracy.” – CCS County Staff

Interviewee Reported CCS County Level Practices Designed to Avoid/Mitigate Delays

The approaches below, *each undertaken by CCS county programs in one or more localities*, may be good examples of replicable improvements to reduce administrative delays in securing medically necessary DME and medical supplies for CCS children. CCS counties could:

- Issue CCS payment authorization and encourage the vendor to move forward in advance of a payment decision by the private PPO insurer. The CCS authorization for payment is issued and given to the vendor with special instructions indicating that the vendor must submit a request for payment to the private insurer before sending the claim to CCS/Medi-Cal fee-for-service for payment. However, since the authorization is a commitment from CCS that it will pay if the PPO insurer does not, CCS staff encourages the vendor to understand that receipt of the CCS authorization should allow the vendor to order and deliver the equipment without waiting for the private insurer to make a decision regarding whether it will pay; the vendor will get paid by CCS/Medi-Cal fee-for-service, if the private insurer denies.

- Issue authorization and encourage the vendor to move forward in advance of a payment decision by the private HMO. Same process as the bullet above.
- Co-locate a CCS staff person two days a week at the Medi-Cal managed care health plan. This CCS staff person takes responsibility for many aspects of the relationship between CCS and the Medi-Cal managed care health plan, including educating Medi-Cal managed care health plan staff about CCS policies to inform the health plan's decisions regarding authorization of DME and medical supplies.
- Identify an RN liaison with knowledge of DME and medical supplies in the Medi-Cal managed care health plan to work regularly with CCS staff in making determinations that lead to decisions about which of these entities will be responsible for payment.
- Communicate in writing and/or meet in person periodically with the Regional Center to establish clarity regarding equipment and supplies that CCS does not cover under normal circumstances. (See Appendix E: County CCS Letter to Regional Center Regarding DME Not Covered by CCS/Medi-Cal).
- Encourage vendors to accept and act on verbal payment authorizations in advance of the paperwork. When a backlog of cases is causing delays, the CCS County program places a phone call to the vendor letting them know that an authorization will be forthcoming. With this assurance, some vendors are willing to deliver DME.
- When a prescription cannot be obtained timely, issue payment authorizations without formal prescriptions, in cases where there is clear documentation in medical reports that the equipment is medically necessary. This process relies on documentation by physicians within medical reports as adequate documentation of medical necessity and physician intention.
- When a family obtains a prescription from a physician who is not CCS paneled, if the CCS county Medical Consultant consults the records and identifies that the DME and medical supplies are medically necessary for the CCS-eligible condition, he/she will approve the prescription.
- Assign a CCS staff, i.e. a "DME Coordinator," to take responsibility for tracking and expediting all aspects of the administrative process involved with providing DME and medical supplies. This person: tracks the process from the time of the request through to the delivery of the DME or medical supply; tracks the amount of time it takes between steps in the process; serves as a liaison between/among CCS staff and between CCS, the vendor, and other parties; and, holds weekly phone calls reviewing open DME and medical supply orders with a key DME and medical supply vendor and key private plans to impact/improve equipment delivery times.
- One county CCS program has experimented with using an Excel spreadsheet to track key phases of the DME and medical supply process from the time the need for DME or medical supply is identified to the time it is delivered. It is hoped that this sort of tracking will help identify delays that can be addressed. (See Appendix F: CCS County Excel Spreadsheet for Tracking Timing for the Delivery of DME).
- Allow Medical Therapy Program staff to authorize DME and certain medical supplies. This helps to avoid time-consuming back-and-forth processes between therapy and administrative staff. In the case of medical equipment, this allows an expedited process without review by the case manager when, for example, the child needs the next size up of a supply that has already been authorized.

- Include a one-year prescription for DME repairs. This is a trend in many counties but is not yet required statewide.
- Maintain an electronic system to track prescriptions, codes, quotes etc. This electronic system/shared drive allows a staff person who works in multiple locations to efficiently track the DME and medical supply process.
- Include all involved parties (e.g. physician, Medical Therapy Unit, vendor) in communications regarding all denials and authorizations. Including all the players in communications may reduce delay time for parties waiting for a response.
- Ensure that clear guidelines are in place to educate CCS staff including new staff members.
- Educate hospital discharge planners about CCS process for procuring DME and medical supplies. This education process gets repeated periodically when hospital staff changes.
- One county CCS program is considering sharing with CCS families a written flowchart that includes an estimated timeline so families may better understand the process for securing DME and medical supplies and what might be typical expected timelines. (Please see Appendix G: County CCS Flowchart for Parent Education Purposes).

National Health Law Program Survey

During the fall of 2016 the National Health Law Program (NHLP), which serves low-income and underserved people, surveyed professionals serving CSHCN about a range of issues related to health services for children with special health care needs. Of 237 advocates surveyed, 79 responded. NHLP reported the following survey findings:

- About 40% of the respondents identified difficulty for CSHCN in obtaining DME or medical supplies. Twenty-three respondents ranked DME and medical supplies “very difficult” to obtain, and eight more ranked it “difficult.”
- Respondents identified a range of barriers to obtaining DME and medical supplies.
- The most common were lack of family education and information, lack of coordination among programs, and general difficulty working with the agencies tasked with providing services.

Recommendations

The recommendations below address multiple issues underlying delays in CSHCN receiving medically necessary DME and medical supplies timely.

- While some of these recommendations may be initiated at the local level, by and large the state should establish standardized requirements, monitor and enforce policies, and provide support to localities as they implement new approaches.
- In light of the devastating impact the delays have on children, and in light of the impending implementation of the Whole-Child-Model, policymakers should move forward with a sense of urgency to implement these recommendations.
- One or more legislative informational hearings would provide an appropriate forum to support information gathering to address how best to move forward to enact these recommendations.

State and/or local policymakers are urged to:

1. Establish a system to track current time frames and, eventually, establish and monitor reasonable required time frames for final delivery;
2. Monitor and enforce memoranda of understanding between local Medi-Cal managed care health plans and county CCS programs;
3. Require that county CCS programs issue payment authorization to vendors as soon as is feasible to address delays related to private health insurer/HMO payer of last resort issues;
4. Require, monitor, and enforce memoranda of understanding addressing payment responsibility between county CCS programs and Regional Centers;
5. Improve internal county CCS processes;
6. Ensure adequate funding rates to incentivize wider availability of vendors of DME and medical supplies and to ensure adequate levels of program staff;
7. Create wider availability of alternative sources of DME and medical supplies;
8. Establish a state-level advisory function;
9. Establish county-level coordinating councils; and,
10. Support the work of Family Resource Centers and other nonprofit parent-support organizations.

These recommendations are discussed in greater detail below.

1. **Establish a system to track current time frames and, eventually, establish and monitor reasonable required time frames for final delivery.**
 - a. The state should collect data from each county CCS program to **track in a standardized format for one year the time it takes to deliver DME and medical supplies**. The results, including analysis of delays, should be submitted to the state quarterly.
 - b. The state should provide **technical support** for the establishment of standard paperless electronic communication systems within each county CCS program to allow it to track the progress/timeframe of DME and medical supplies through each phase. Timing for each of the many steps in the process should be accounted for from the time the need for DME or medical supplies is identified to when the functioning product is finally delivered to the family and should include opportunities to identify when delays are attributed to entities outside of CCS, including public and private party payers as well as vendors.
 - c. Following its analysis of the data collected pursuant to 1a above, and taking into account other factors including the impact delays have on CSHCN, the state should **identify a reasonable minimum timeframe for the delivery of DME and medical supplies**. This timeframe, beginning at the time the need for equipment/supplies is identified and extending to when the equipment is delivered to the family and fully functioning, may vary depending on the customization of the equipment. The state should require periodic reporting from county CCS programs regarding compliance with these timeframes. The state should require that each county CCS periodically analyze cases where time frames are not met and submit this analysis to the state including explanations for delays and, where appropriate, a plan of correction.
 - d. DHCS should ensure an **annual patient experience survey** of all or a sample of CCS enrollees that includes but is not limited to specific questions about timely DME and medical supply access. Survey questions could be incorporated into existing surveys. A similar survey should be conducted with hospitals that serve CCS children. The surveys could be administered statewide by DHCS or delegated to county CCS programs.
 - e. As part of the timeframe processes described above, the state should support Family Resource Centers to **gather information from parents regarding the impact of delays on CSHCN** and their families when timeframes described above are not met and to describe what was done by the CCS program to mitigate that impact.

2. Monitor and enforce memoranda of understanding between local Medi-Cal managed care health plans and county CCS programs.

MOU between county CCS and Medi-Cal managed care health plans should be explicit that, when CCS determines that it is not responsible for funding particular DME or medical supplies in the case of a particular patient, the Medi-Cal managed care health plan must immediately act as payer and can later seek reimbursement from CCS, as appropriate. Also, the Medi-Cal managed care health plan should ensure that independent provider associations (IPAs) it contracts with honor the MOU commitments. The state should monitor and enforce these MOU provisions.

3. Require that county CCS programs issue payment authorization to vendors as soon as is feasible to address delays related to private health insurer/HMO payer of last resort issues.

- a. It is common for CCS Medical Therapy Program patients to have private health insurance coverage. Private insurers are required to be primary payers with CCS as the secondary payer. The process of providing DME and medical supplies waits while private insurers decide whether it is a covered benefit as well as whether payment will be denied or authorized based on medical necessity. In the case of children covered by CCS, the state should advise vendors that they should begin filling the DME or medical supply order as soon as they receive a CCS authorization; the state should assure vendors that CCS will pay in cases where the private insurer finally denies payment.
- b. The state should change policies so that county CCS programs are required to respond to cases in which families have HMO coverage as recommended above in cases of other private insurance coverage. That is, CCS should not delay payment authorization for DME and medical supplies; and, as above, CCS should advise vendors that they should begin filling the DME or medical supply order as soon as they receive a CCS authorization.
- c. To expedite decisions regarding authorizations, the state should require that private health insurers – PPOs, HMOs, and other private health insurance products – designate lead persons, who have experience and expertise in CSHCN and their DME and medical supply needs, to be responsible for authorizations/denials regarding DME and medical supplies.

4. Require, monitor and enforce memoranda of understanding addressing payment responsibility between county CCS programs and Regional Centers.

The state should require that MOU be established between local CCS programs and Regional Centers. The state should provide standardized MOU language that makes explicit which entity shall be responsible for payment in the case of various types of DME and should also outline an efficient required process between the two entities should discrepancies arise. The state should enforce these MOU provisions.

5. Improve internal county CCS processes.

- a. To avoid slowdowns that occur when staff responsibilities for DME and medical supply authorizations are fragmented among multiple staff, including staff that is not fully familiar with DME and medical supplies, **CCS county programs should consolidate the responsibility for tracking and final approval of DME and medical supply authorization into the hands of one or more staff with DME and medical supply expertise and training.** This staff's responsibilities may include communicating clearly to all involved CCS staff and paneled physicians as well as to outside entities including local vendors and local Medi-Cal managed care health plans, private insurers, schools, Regional Centers and with the families of CCS children regarding important process details and best practices that support more timely delivery of DME and medical supplies.

In addition, staff responsibilities may include tracking the process from the time the DME or medical supply need is identified through to the prescription and authorization process and delivery to the family. This person(s) should be empowered to identify and address delays as they occur within CCS, including identifying needed policy changes when appropriate. This person(s) should establish relationships and identify and address delays with outside entities including working with: private insurers regarding gathering information and issuing timely authorizations, denials, and appeals; vendors on issues related to obtaining quotes and equipment timely, authorizations, and billing issues; and hospitals regarding timely notification of patient discharge. This person(s) should have responsibility for supporting families regarding: their role; their expectations regarding timeliness; and working through processes regarding payer of last resort issues including appeals when necessary.

- b. The state should change policies to allow **automatic reauthorization in certain cases** where a child's medical condition is not expected to change and the need for particular equipment and/or supplies is expected to stay constant over time. The state should appoint an ad hoc/short-term committee of clinicians, families, advocates, and other key stakeholders to identify in which cases and over what time periods automatic reauthorization is appropriate, as well as under what circumstances a visit to a clinician is important prior to reauthorization. In this process, the committee should consider automatic reauthorization under certain circumstances for, among other things: G-tube/feeding supplies; BiPAP supplies; respiratory supplies; trach supplies; catheter supplies; diabetes supplies; and incontinence supplies. In cases where reauthorization continues to be required the state should **require that an electronic interface be created between the vendor and CCS providers** to ensure that reauthorization prescriptions can be generated timely.
- c. The state should require that a **prescription good for one year for DME repairs/size modifications** be on hand in the case of CCS children who have DME needs for specified equipment.

6. Ensure adequate funding rates to incentivize wider availability of vendors of DME and medical supplies and to ensure adequate levels of program staff.

- a. The state should provide **increased/adequate payment rates for DME items and for medical supplies** to encourage healthy competition and thus improve customer service, including timeliness, among **vendors** who serve CCS children.
- b. The state should provide **adequate funding** to programs that serve children with special health care needs to **ensure that there is adequate staff to expedite the provision of DME and medical supplies** in a timely manner, thus avoiding delays in the provision of DME and medical supplies and also avoiding the imposition of unnecessary involvement in bureaucratic affairs by families of CSHCN.

7. Create wider availability of alternative sources of DME and medical supplies.

In some California counties the limited number of vendors who contract to provide DME and medical supplies for CCS children contributes to delays. The state should **allow that certain DME and medical supplies may be dispensed by providers other than currently approved vendors.** The state should establish policies that would allow easily accessible pharmacies (e.g. Target, Walgreens, Walmart, etc.) to provide certain non-custom “off-the-shelf” items funded by CCS including some crutches, grab bars, shower chairs, transfer benches, commodes, hospital beds, portable ramps, etc. as well as short-term rental equipment. Medical therapists should be involved to assure that the product the family receives is good quality, appropriate, fits the child, and fits well in the child’s home environment.

8. Establish a state-level advisory function.

DHCS should establish an ongoing state level advisory group – or assign responsibilities to a subcommittee of an existing state level advisory group – including representatives from CCS, Regional Centers, Medi-Cal managed care health plans, schools, private insurance, families, and advocates to identify and address issues related to timely access to DME and medical supplies and to make recommendations regarding needed resources to address these barriers including determining how best to:

- support the enactment and enforcement of the recommendations above;
- support the interpretation and enforcement of existing statutory/regulatory/contractual/MOU requirements to favor timely delivery of DME and medical supplies with as little administrative hassle as possible, particularly reducing administrative hassle for families;
- identify and address the need for new and/or amended public policies including laws/regulations/numbered letters/all plan letters/contractual/MOU arrangements necessary to support the changes recommended above;
- encourage best practices be undertaken at the county level agencies; and,
- support local – county level or regional – entities comprised of representatives from multiple agencies to address system-level care coordination related to securing DME and medical supplies.

9. Establish county-level coordinating councils.

County-level advisory groups should be established to address local policies that govern the process of accessing DME and medical supplies. These advisory groups should meet periodically, review family and hospital survey results and recent experience, and determine whether changes should be made to processes related to DME and medical supplies. These advisory groups should include representatives from CCS, Medi-Cal managed care health plans, private insurers, schools, advocates, and families to identify and address issues related to timely access to DME and medical supplies and needed resources to address these barriers. These Advisory Groups should review delays that have been identified during the year and identify processes that may be put in place to address the delays, including:

- care coordination/fostering clear communication amongst agencies to most efficiently address payer-of-last-resort issues;
- setting up skillful communications processes including: in-person training regarding eligibility criteria at multiple agencies; co-location of staff; regularly-scheduled interagency meetings; internet-based information to educate key staff to understand eligibility policies and procedures of other county programs;
- working with local hospitals to encourage them to provide adequate advance notice of hospital discharge and DME and medical supply needs to payers and vendors whenever possible to allow a reasonable timeline to conduct, as needed, site visits to the family's home, family training and to order equipment, with customization as needed; and,
- identifying and encouraging best practices including some current county-level practices identified in this issue brief.

10. Adequately support Family Resource Centers and nonprofit organizations that train and educate CCS families.

While these reforms would free families from time-consuming bureaucratic entanglements to spend more time caring for their children and attending to other family/life responsibilities, it will be important that families continue to have input in their child's DME and medical supply needs at key junctures.

- To support the effectiveness of this input, it will be important that families continue to be well educated about DME and medical supplies that should be available to their child and the processes for obtaining them and expectations regarding timeframes. Particular attention should be devoted to families who are low income, lack education, hold multiple jobs, are not native English speakers, are not health literate, or lack experience moving bureaucracies.
- Family Resource Centers and other nonprofit parent-support organizations will need to continue to play an important role in educating parents about how best to advocate on behalf of their own children.

Appendix A: List of Interviewees

Terri Alesci, MS, Supervising Therapist
Medical Therapy Program, Sacramento County California Children's Services

David Alexander, Medical Therapy Supervisor
California Children's Services Shasta County

Dyan Apostolos, Assistant Public Health Bureau Chief
Monterey County Public Health Bureau

Michael Ballance, Therapy Case Manager
Armando Valerio PT, DPT, Therapy Services Manager
California Children's Services Medical Therapy Program
San Joaquin County Public Health Services

Christine A. Betts, MA, PT, Supervising Therapist
Monterey County California Children's Services Therapy Program

Edward A. Bloch, MD, FAAP, Medical Director
Los Angeles County Department of Public Health

Ellen Burke, OTR/L, Occupational Therapist
Medical Therapy Unit Case Management
California Children's Services, Martinez

California Community Care Coordination Collaborative (5Cs), Members
Lucile Packard Foundation for Children's Health

Faisal Chawla, MD, Physician Advisor
Inpatient Pediatrics, Children's Hospital Los Angeles

Julie Clark with Kathy Devine, Lead Nurses
Alameda County California Children's Services

Janice Darche, PT, Assistant Chief Therapist
Alameda County California Children's Services

Harriet Fain, PT, MPA, Interim Division Manager, California Children's Services, Chief,
Medical Therapy Program
Orange County California Children's Services

Carolyn Foster, MD, Health Services and Quality of Care Research Fellow / Acting Instructor
Department of Pediatrics – University of Washington School of Medicine
Seattle Children's Hospital Research Institute – Center for Child Health, Behavior, and Development

Amy Hamm, Registered Nurse
Orange County Regional Center

Tonya Hammatt, Director of Payer Relations
Jaye Palladino, Area Funding Director
Pacific National Seating & Mobility

Deanna Hanson, Certified Orthotist
RayTegerstrand's Prosthetics & Orthotics

Catherine Hayashida, PT, Senior Physical Therapist
Cynthia Ullman, OTR/L, Senior Occupational Therapist
Judy Bachman, PT, Rehab Coordinator
San Francisco Department of Public Health
California Children's Services Medical Therapy Program

David Hayashida, MD, Former Medical Director
San Francisco California Children's Services

Siem Ia, RN, MS, CPNP, Pediatric Nurse Practitioner
Pediatric Medical Home Program at UCLA

Maria Iriarte JD, Attorney
Disability Rights California

Mike Keeley, Director of Client Services
San Andreas Regional Center

Dave Kramer-Urner, PT, Senior Health Services Manager
J. Leticia Valencia, Medical Care Program Eligibility Supervisor
Karin Stohn, MTP Supervising Therapist
Children's Medical Services and Vital Statistics, Santa Cruz County

Kevin Low, DPT, Senior Therapist
North Salinas Medical Therapy Unit, Monterey California Children's Services

Pip Marks, Manager
Allison Gray, State Leadership Liaison
Family Voices Council
Family Voices of California

Patricia McClelland, Systems of Care Division Chief
Annette Lee, Chief, Waiver and Research Section and,
Systems of Care Division, California Department of Health Care Services

Myra Medina, DPT, Doctor of Physical Therapy
Supervisor, Conejo Medical Therapy Unit
Project Coordinator, VC-Pact
Ventura County Public Health

Deborah Murr, Administrative Director of Health Services
Kern Health Systems

Justin Koenig, PT, (formerly) California Children's Services DME Coordinator
Alameda County Public Health

Mona Patel MD, Medical Director
Patient Centered Medical Home
Altimed Outpatient Clinic
Children's Hospital Los Angeles

Jeff Powers, MHA, RPT, Physical Therapy Consultant
California Children's Services Program
Department of Health Care Services

Sherry Rendel, Public Health Nurse
Barbara Facher, Social Worker
Alliance for Children's Rights.

Marilyn Romero, MSN, RN, PHN, California Children's Services Nurse Manager
Family Health Services Division, Alameda County Public Health Department

Lisa Rosene, LCSW, Director, Regional Center Services
Golden Gate Regional Center

Barbara Sheehy, MS, (formerly) Mental Health Initiative Coordinator
California Children's Services Program, Family Health Services Division, Alameda County
Public Health Department

Laurie A. Soman, Director, CRISS Project
Director, Alameda County Medical Home Project
Senior Policy Analyst, Lucile Packard Children's Hospital

Lisa Tedlos, Supervising RN
Sacramento County California Children's Services

Marc Thibault, Project Director
Kern County Medically Vulnerable Care Coordination Project

Peg Walden, California Children's Services Administrator
Naomi Loudon, Health Services Section Manager

Anna Evenson, Supervising Public Health Nurse
Lisa Sereni, Senior Public Health Nurse
Sonoma County Department of Health Services

Brian Winfield, Deputy Director
Community Services Division, Department of Developmental Services

Appendix B: List of Family Voices of California Survey Questions

1. Please list any concerns or problems you've had with DME.
2. If possible, please provide specific, real-life examples of when access to DME has been an issue.
3. Has your child ever had to remain in the hospital because he/she was waiting for a specific piece of DME? Please describe.
4. Outside of a hospital setting, have you ever had to wait an extended period of time for DME? How long? Please describe.
5. How have delays in getting DME impacted your child?
6. As a parent/caregiver, how does time spent dealing with DME delays impact the care of your child?
7. Have you ever paid for DME out of pocket when you felt it should have been covered by another party? Please describe.
8. In the case of your family (or families you know), are delays in getting DME ever related to the time it takes for decision to be made by others about who is responsible for paying for the equipment? Please describe.
9. Please outline possible solutions to the DME problems you've encountered.
10. Please feel free to add anything else you feel the DHCS should be aware about concerning DME.

Appendix C: Medi-Cal List of Durable Medical Equipment, Orthotics, Prosthetics, and Medical Supplies

The link below is to a Medi-Cal webpage that includes details regarding durable medical equipment, orthotics, prosthetics, and medical supplies at the following links on the webpage:

- Contents (Part 2 – Medi-Cal Billing and Policy): Durable Medical Equipment and Medical Supplies;
- Orthotic and Prosthetic Appliances, Billing Codes and Reimbursement Rates – Orthotics; and,
- Orthotic and Prosthetic Appliances: Billing Codes and Reimbursement Rates – Prosthetics.

[Durable Medical Equipment and Medical Supplies \(DME\)](#)

Appendix D: List of Children's Regional Integrated Service System (CRISS) Durable Medical Equipment Access Survey Questions

1. Have you seen a change in the status of large vendors such as Apria and Shield in your area?
2. Are you experiencing situations with CCS babies and children kept in the hospital past the point where they could be discharged because necessary equipment can't be obtained?
3. Are you experiencing any of the following situations re: DME or medical supplies? Check all that apply.
4. (For Hospital Representatives Only) If your hospital is paying for DME/supplies, what do you estimate is the annual cost? How do you pay for the DME/supplies (e.g. hospital budget, donations)?
5. Have you seen families experience significant financial hardship due to the cost of DME/medical supplies?
6. Is there anything else about your experience with access to DME or medical supplies that you think CRISS should know?

Appendix E: County CCS Letter to Regional Center Regarding DME Not Covered by CCS/Medi-Cal



County of [REDACTED]

HEALTH SERVICES AGENCY

[REDACTED] MEDICAL THERAPY UNIT

TELEPHONE: [REDACTED]

FAX: [REDACTED]

PUBLIC HEALTH DIVISION
CALIFORNIA CHILDREN SERVICES

[REDACTED]
[REDACTED]
[REDACTED] Regional Center
[REDACTED]
[REDACTED]

September 28th, 2015

Dear [REDACTED],

I am writing to provide you with information about Durable Medical Equipment (DME) that are not, under normal circumstances, benefits of the CCS/Medi-Cal program. This information should allow us to dispense with the provision of a formal CCS denial in these clear-cut instances, thus streamlining your efforts in providing your clients with needed equipment.

The following items are not a CCS benefit:

- | | | |
|-----------------------------------|---|---------------------------------------|
| Bicycles | Any item requiring installation | Van lifts/Vehicle modifications |
| Bolsters | (including installed ceiling track lifts) | Wedges |
| Car seats (for under 6 years old) | Motorized caster carts | Weights |
| Crawlers | Personal computers & accessories | Wheelchair canopies |
| Cribs | Sand bags | Wheelchair carriers & tie-downs |
| Exercise mats | Strollers | Convenience accessories for mobility |
| Fixed recline wheelchairs | Swings | (e.g., book bags, diaper bags, horns, |
| Generators | Tricycles | mirrors, etc.) |

Should there ever be a question about any of these items in a specific case, please feel free to call me.

Thank you for working with me to improve the coordination and timeliness of the services we provide our clients.

[REDACTED]
[REDACTED]
[REDACTED]



Public Health
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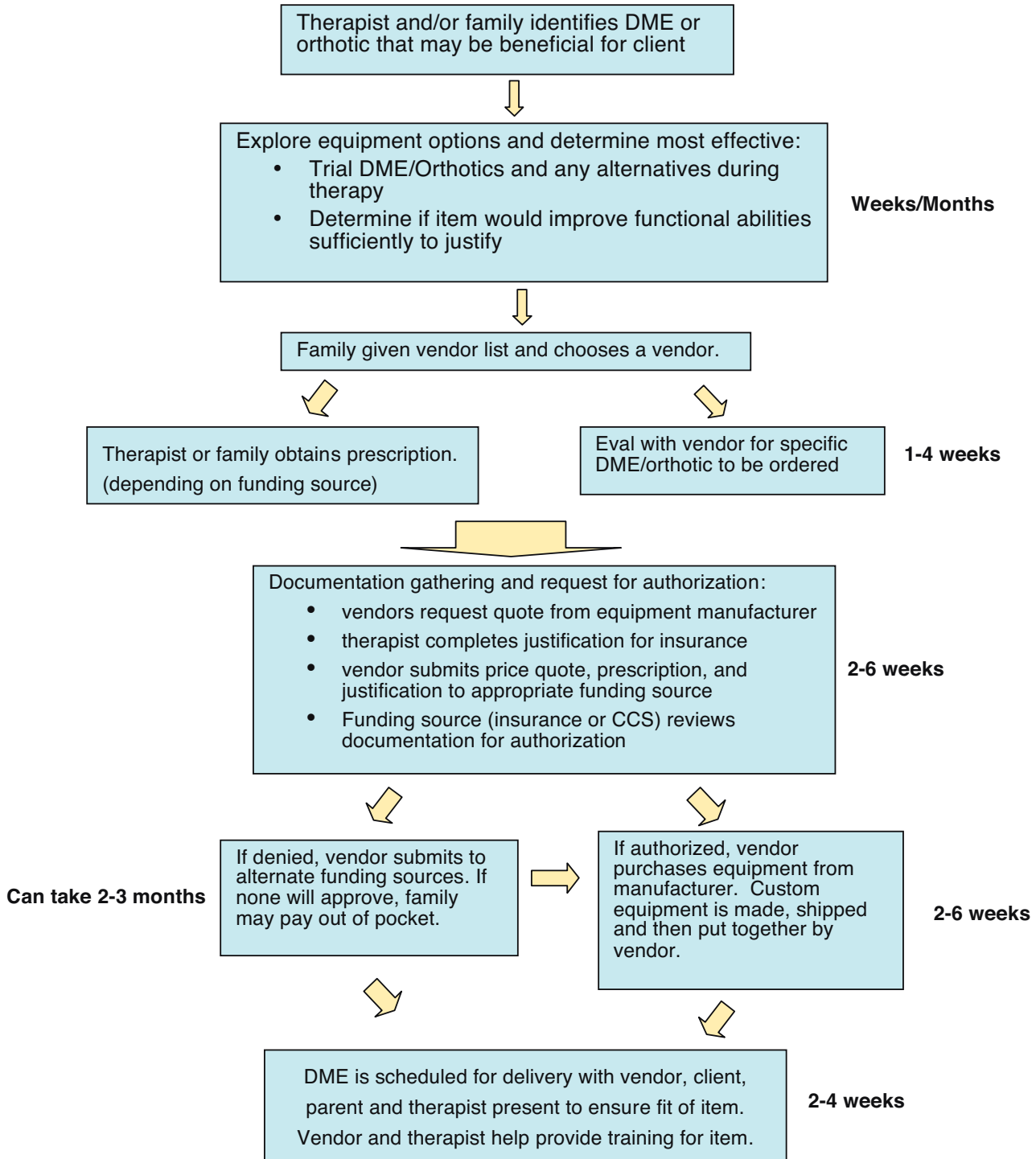
Appendix F: CCS County Spreadsheet for Tracking DME Timing

Unique Identifier	Equipment Type	Date Parent / Client Identified Need to CCS Responsible Party (therapist, doctor, vendor, etc.)	Date Therapist Became Aware	Date Vendor has Info Needed to Create a Quote (not including Rx or justification)	Date Rx Received by Vendor?	Date CCS Received Authorization Request from Vendor (may not include all info needed for authorization)	Date CCS has All Information Needed for Authorization (vendor quote, Rx, justification, etc.)	Date CCS Issued Authorization	Date DME Delivered	Total Days from Start to Finish
	Car Seat	5/20/17	5/21/17	5/22/17	5/24/17	5/24/17	5/25/17	5/26/17	5/27/17	7
	Activity Chair	6/3/17	6/3/17	6/4/17	6/4/17	6/4/17	6/5/17	6/5/17	6/6/17	3
	Manual Mobility Device	7/4/17	7/5/17	7/5/17	7/5/17	7/5/17	7/5/17	7/5/17	7/5/17	1
	Bath Chair	6/7/17	6/7/17	6/8/17	6/8/17	6/9/17	6/10/17	6/10/17	6/11/17	4
	Car Seat	6/19/17	6/19/17	6/20/17	6/20/17	6/20/17	6/21/17	6/22/17	6/23/17	4
	Hospital Bed	7/11/17	7/11/17	7/11/17	7/12/17	7/12/17	7/12/17	7/13/17	7/13/17	2
	Activity Chair	7/19/17	7/19/17	7/20/17	7/20/17	7/20/17	7/20/17	7/21/17	7/21/17	2
	Manual Mobility Device	7/5/17	7/5/17	7/6/17	7/7/17	7/10/17	7/11/17	7/11/17	7/13/17	8

The dates used in Appendix F are examples, and do not represent dates from actual cases.

Appendix G: County CCS Flowchart for Parent Education Purposes

Timeline for DME/Orthotics Process



References

1. The Child and Adolescent Health Measurement Initiative. (2013, January). *Children with Special Health Care Needs: A Profile of Key Issues in California*. Retrieved from <http://www.lpfch.org/publication/children-special-health-care-needs-california-profile-key-issues>.
2. As of 2015 approximately 200,000 children ages birth-21 were active CCS enrollees. kidsdata.org. (2017). Active California Children's Services (CCS) Enrollees, by Age Group. Retrieved from <http://www.kidsdata.org/topic/600/special-needs-ccs/table>
3. While the program is primarily for low income children, CCS covers specialty care for medically-eligible children in higher-income families when the cost of their child's care reaches a certain level.
4. California Department of Health Care Services, California Children's Services. (2016, January). Overview of CCS Medical Eligibility. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Pages/medicaleligibility.aspx>
5. Smith,K., Soman, L. A., Duenas, J. et al. (2009, December). *California's Service System for Children and Youth with Special Health Care Needs: Analysis and Recommendations for A Service System That Works for Children and Families*, 35-36. Retrieved from <http://www.lpfch.org/sites/default/files/field/publications/servicesystemreport.pdf>
6. California Department of Health Care Services, California Children's Services. (2015, July). Program Overview. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Pages/ProgramOverview.aspx>.
7. The current exception to this carve out is for residents of Napa, San Mateo, Santa Barbara, Solano, and Yolo counties.
8. Smith,K., Soman, L. A., Duenas, J. et al. (2009, December). *California's Service System for Children and Youth with Special Health Care Needs: Analysis and Recommendations for Service System That Works for Children and Families*, 37. Retrieved from <http://www.lpfch.org/sites/default/files/field/publications/servicesystemreport.pdf>.
9. See discussion regarding Whole-Child-Model, County Organize Health System counties which are an exception, page 12.
10. This standard contract language is included in DHCS contracts with Medi-Cal managed care health plans in California's "two-plan" counties. <http://www.dhcs.ca.gov/services/Pages/Medi-CalManagedCare.aspx>
11. In the small number of cases in which children are eligible for CCS but not eligible for Medi-Cal, CCS authorizes payments from its non-Medi-Cal funds.
12. CCS children whose parents have died or who are disabled young adults may be Medicare eligible. In these cases, if the DME need is a covered Medicare benefit, Medicare is expected to be the primary payers with Medi-Cal a secondary payer.

13. DHCS All Plan Letter 15- 018, July 9, 2015, calls for Medi-Cal managed healthcare plans “... to ensure that medically necessary equipment is provided to Medi-Cal beneficiaries in a timely manner...”; DHCS CCS Numbered Letter 09 – 0703, August 8, 2003, Subject: Revised CCS Guidelines for Recommendation and Authorization of Rental or Purchase of Durable Medical Equipment – Rehabilitation (DME-R), Attachment 1 CCS Guidelines for Recommendation and Authorization of Durable Medical Equipment-Rehabilitation (DME-R), page 1, calls for CCS staff to make “... timely and appropriate DME-R decisions.” However, neither Medi-Cal nor CCS provides guidance regarding what timeframes are considered “timely” for delivery of DME and medical supplies to CCS children. Both All Plan Letters can be found at: California Department of Health Care Services. (2017, July). Managed Care All Pan Letters – 1998 to Current. Retrieved from <http://www.dhcs.ca.gov/formsandpubs/Pages/AllPlanLetters.aspx>.
14. California Department of Health Care Services, California Children’s Services. (2017, July). California Children’s Services (CCS) Whole-Child Model (WCM). Retrieved from <http://www.dhcs.ca.gov/services/ccs/Pages/CCSWholeChildModel.aspx>.
15. The 21 counties in which the whole Child Model will be implemented are: San Luis Obispo, Santa Barbara, Merced, Monterey, Santa Cruz, San Mateo, Orange, Del Norte, Humboldt, Lake, Lassen, Marin, Mendocino, Modoc, Napa, Siskiyou, Shasta, Solano, Sonoma, Trinity and Yolo counties.
16. Some County Organized Health Systems are expected to begin implementation in 2018, others in 2019. *Phase-In Methodology, Whole Child Model*. (2017, January). Retrieved from California Department of Health Care Services: <http://www.dhcs.ca.gov/services/ccs/Documents/PhaseInDocument.pdf>
17. California Department of Health Care Services. (2017, January). *California Children’s Services Program (CCS) Whole-Child Model Frequently Asked Questions*, 6. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Documents/FAQs.pdf>
18. California Department of Health Care Services. (2016, October). *Whole-Child Model and SB 586 Overview*. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Documents/WCMModelSB586.pdf>
19. See page 13 for a discussion of payer relationship between CCS and private HMO coverage.
20. California Department of Health Care Services. (1994, March 10). *DHCS CCS Numbered Letter 06 – 03942, Subject: Required Use of Health Insurance*, 2-3.
21. In cases where the private insurer agrees to pay, if the private insurer does not pay the entire amount billed by the vendor, then CCS/Medi-Cal may pay the balance for the DME or medical supply, up to the amount Medi-Cal would have paid, had it been solely responsible for the cost.
22. California Department of Health Care Services. (1994, March 10). *DHCS CCS Numbered Letter 06 – 03942, Subject: Required Use of Health Insurance*, 3-4.
23. Special Education Local Plan Areas (SELPAs) were created when school districts and county school offices in California were required to form geographical regions to provide for all special education service needs of children residing within the region’s boundaries. Special Education Local Plan Area Administrators of California. (2017). What is a SELPA? Retrieved from <http://www.selpa.info/what-is-a-selpa/>.
24. California Department of Health Care Services. (2007, January 4). *CCS Information Notice No.: 07 – 01, Subject, Revised Interagency Agreement (IA) between California Department of Health Services, CMS Branch and California Department of Education (CDE), Special Education Interagency Cooperative Agreement*, 5-6. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Documents/ccsin0701.pdf>.

25. Attachment 1 CCS Guidelines for Recommendation and Authorization of Durable Medical Equipment-Rehabilitation (DME-R), p. 2 from California Department of Health Care Services. (2003, August 8). CCS Numbered Letter 09 – 0703, Subject, Revised CCS Guidelines for Recommendation and Authorization of Rental or Purchase of Durable Medical Equipment – Rehabilitation (DME-R).
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27. California Department of Health Care Services. (2014, May 2). *CCS Information Notice: 14 – 05, Subject: Impact of Special Education Due Process Hearings on the CCS Program and the Medical Therapy Program (MTP)*, 3. Retrieved from <http://www.dhcs.ca.gov/services/ccs/Documents/ccsin1405.pdf>.
28. State of California Department of Developmental Services. (2016, April). DDS Transparency Portal. Retrieved from <http://www.dds.ca.gov/Transparency/>.
29. Lanterman Developmental Disabilities Service Act, California Welfare and Institutions Code Section 4512 (a) (B). (2016, January 1). Retrieved from <http://www.dds.ca.gov/statutes/docs/lantermanAct.pdf>.
30. California Welfare and Institutions Code Section 4659.10. (2014, June 20). Retrieved from http://leginfo.legislature.ca.gov/faces/codes_displaySection.xhtml?lawCode=WIC§ionNum=4659.1.
31. Please see Appendix E: County CCS Letter to Regional Center Regarding DME Not Covered by CCS/Medi-Cal
32. The Medical Therapy Program is a special program within California Children's Services that provides physical therapy occupational therapy and medical therapy conference services, among other things.
33. Medi-Cal Update, Durable Medical Equipment and Medical Supplies, July 2017, Bulletin 502 # 4 "Face-To-Face Encounters" calls for the following regarding DME approval processes: "Effective for dates of service on or after July 1, 2017, *Code of Federal Regulations* (CFR) Title 42, Section 440.70 requires Medicaid programs to allow reimbursement to providers only for Durable Medical Equipment (DME) items that are signed for by a physician in either written or electronic format. Additionally, a face-to-face encounter administered by a physician, nurse practitioner, clinical nurse specialist or physician assistant, related to the primary reason the recipient requires the DME item, is also required. If the provider performing the face-to-face encounter is not the physician, the provider must communicate the clinical findings of that face-to-face encounter to the ordering physician." Retrieved from <https://files.medi-cal.ca.gov/pubsdoco/bulletins/artfull/dme201707.asp#a4>.
34. DHCS/Medi-Cal approved vendors are not compelled to provide all medically necessary DME and medical supplies for CCS children.