

DME Survey & Story Collection for DHCS' CCS Redesign Team

2.10.17

Please list any concerns or problems you've had with DME.

- Getting repairs to existing equipment, and demos out to the home for new equipment is an extremely lengthy process, taking up to months and more; even when it has been flagged as an emergency repair to equipment that is unsafe. CCS response is to discontinue use of equipment; which in the specific case of a bath/toileting chair is dehumanizing and significantly compromises quality of life.
- Majority of times it gets denied and have been asked to provide "more supporting documents" Even when done they still decide to deny patient and will cause that I ask, if available, managed care to pay for DME for patient.
- prescriptions being lost, prescriptions not being in the right form, doctors medically necessitated items being denied prescription expires before item received, having to start over insurance providing lower cost item not a covered benefit items denied not current with times items provided then item not covered when time for a replacement supply companies not providing correct order supply company not fulfilling the order supply company choosing what it sends to save themselves money vendorization of needed provider this is just the tip of the iceberg.
- The only issues I've had for my child is when she needed modifications they would charge extra.
- Getting repairs to existing equipment is very inconsistent and time consuming.
- My son's wheelchair breaks often and it's hard to get a tech out to fix it in a timely manner. He's also had ankle foot orthotics break numerous times and the replacement process is long. He requires the braces to walk.
- Obtaining oxygen coverage for a pediatric congenital heart patient
- The vendor did not want to sell us a stander even though both our primary insurance and secondary Medi-Cal covered it because they said it wouldn't make enough profit to make it worth it. We had to go to a different location of the same vendor to get it.
- It takes so long to get equipment that by time you get it, the child has grown or changed and you have to start all over.
- Unreasonable delays from the approval process, inadequate equipment (i.e. Inappropriate head support) delivery delays, lack of transparency in process and availability of choices/selections. The process takes unfair and undue advantage of children and families with disabilities that can only access the community with wheelchair vans. I think greater scrutiny of dealers/RC and support for consumers is overdue and in violation of the Lanterman Act and ADA.
- Children being able to trial equipment outside of CCS therapy and so could not pass the 'test' to receive the equipment. CCS insurance does not cover enough of the cost of equipment the child needs and so no vendors will order it because of low reimbursement. Personal Insurance won't send a denial letter until the equipment is purchased, but CCS won't cover the cost unless a denial letter is provided, so the equipment is not able to be ordered.
- Insurance coverage, how long it takes to get it, maintenance on equipment as well as support or help using it.

- I cannot get good maintenance on my son's wheelchair. The only guy who could manage it has died, and we just can't get competent service anymore.
- Acquiring equipment for our son can be a very confusing and challenging task. I find this mostly due to the fact that navigating available services through the state and/or school district confusing. I am very fortunate to have a husband who is very good at trudging through paperwork. I am also very fortunate to have a strong MTU through CCS that helps me to navigate these things. Otherwise I would be totally lost and confused.
- The process is lengthy, inefficient, my child's paperwork has been misplaced, lost. Repairs when scheduled are only partially addressed. DME is incredibly difficult to manage, obtain, maintain...
- It takes a long time to get any equipment. Often, the process is stalled and we don't understand where/why, or what needs to be done to move it along. Sometimes, even after we get the equipment, we receive a bill for it when it should have been covered.
- the main problem that I have had is that I having to prove that my daughter cannot go up the stairs and if there is a bathroom or a small bedroom the size of a closet then that is what she can use instead of thinking about that just maybe she might want to go upstairs in her own home
- The process to obtain DME through CCS took over two years. Referrals and prescriptions continually were misplaced or miscommunicated. I'm a regional center caseworker and have had to do a lot of micromanaging and hovering to ensure that the process was continuing.
- Obtaining the equipment in a timely manner.
- It takes too long to get ccs to order the equipment.
- The business method seems to be deny, deny, deny for any DME. Only the parents who keep fighting have any hope of getting an approval. 2. When my daughter was being fitted for her first wheelchair, the CCS therapist had the equipment vendor come and we were told "choose A or B, those are your only options". When we questioned why we were being given only 2 choices, and why both were inappropriate for her specific needs, we were told "because this is it".
- I have had extensive issues with DME, but to summarize, the length of time it takes to get the equipment is crazy - it can take a year to get a wheelchair - and we have waited. We needed replacement parts - months and months pass before we get anything. We have needed a new back after a surgery my daughter had - the back was incorrectly ordered 3 times. We switched vendors and received the correct one within 3 months. These are just some of the issues - primarily it boils down to the knowledge of the vendor and the length of time it takes to get equipment.
- After my son's surgery we were not able to get the special hospital bed he needed to protect him from causing harm to the surgical site. It was very delicate surgery on his chest and he had to sleep as upright as he could. We tried everything and limped our way through recovery. My son has autism so the hospital bed would have been a much better option than me having to sleep next to his bed for weeks adjusting pillows all night long.
- I had a difficult time obtaining DME. We required a wheelchair with 5 point harness for my 6 year old - because he was mobile, there were questions as to if he needed this. He did require restraint - as he was a danger to himself and attacked me. We were however approved and had special custom fitting through Valley Mountain Regional center.
- Limited resources available for services due to our rural area. Also, there have been times where CCS seems to "lag" on services so that the client ages out.

- I have a consumer who is non-ambulatory and seizures, he doesn't qualify for any DME.
- Securing equipment that fits appropriately 2. Delay in receiving equipment due to physician not writing rx with the language required by CCS 3. delay in receiving equipment in general 4. Not receiving return calls from case manager for support through the process
- Major delays with parts for wheelchair coming from various vendors. Vendors being disorganized, lack of communication.
- Expense for basic equipment was very high. Seems like prices were inflated for insurance coverage to pay. I bought equipment out of pocket at drugstore and it was 70% less on average.
- It is often difficult for Cystic fibrosis patients to get nebulizer cups. CCS covers only one cup per six months. In actuality, several cups are needed in any time because patients nebulize several different medications. And medications often cannot be mixed in the same cup.
- Did not receive the agreed upon power chair. We paid for iLevel out of pocket but did not receive iLevel but instead a substandard iLevel - we found this out at an Abilities Expo and the vendor told us this. We are currently waiting for the power chair that we originally requested.
- My biggest problems has to do with CCS requirements on clients receiving equipment based on MTU and a CCS doctor's prescription. 1st if my child's primary care recommends a piece of equipment it should be sufficient to cover a doctor's prescription. Having to go to a CCS doctor is very hard and difficult process. CCS doctors are overcrowded and very busy and hard to reach due to their specialty. In the bay area this can mean a very long drive to Oakland Children's Hospital for a 6 month appointment open time window which charges for parking \$9. This is very expensive and having a child in a wheelchair it's very hard to obtain close and inexpensive parking. The MTU does not do an education on what equipment is available to the parents at specific ages such as you can't get a wheelchair and an activity chair at the same time. Having a child that can't sit without assistance is often not completely comfortable feeding a wheelchair. Also the requirements for a hospital bed is very distressing. My child definitely met all requirements to have a hospital bed but was put through many denials and heartache before it was approved she went 2 years before it was approved. In the meantime I was told to put my completely disable child on the floor on a mattress which lead to her Gtube coming out multiple times because she would roll off the mattress. Also CCS would not approve a lift and my child lives 14 steps upstairs and the stairs are curved CCS only would give a manual stair lifter and we tried to use it with DME provider, CCS representative, and MTU therapist we all almost dropped her down the stairs because the stair climber could not handle the curve. We had to wait 2 years for regional center to approve an electric stair lift.
- Laborious, bureaucratic, lengthy, byzantine process only accessible to families who can spend time on advocacy and tracking
- No one understood how to bill for our othodics
- 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 who which party was supposed to be held responsible. The fact that providers were also in different counties made it even harder. Through our private insurance we go to Kaiser in Oakland, however the Medi-Cal MCO was Partnership and the CCS office was in Solano. There needs to be better communication and a variety of scenarios thought about in the redesign.
- Lengthy wait time for the availability of the vendor and CCS authorization

- CCS has been pretty useless to us. I am the one that has to follow up With everything.. from making sure they have rec'd the prescription, forwarding it, getting the specs to them from the inept supplier to making sure the request is sent to Medi-CAL.
- CCS is very resistant to authorizing equipment. They make it difficult for families with special needs
- Yes, I am a nurse and special educator and I speak English and we have had 2 private insurances. We have for 23 years struggled every time my son who has Cerebral palsy needed new DME. I have often felt discriminated against for even having insurance. Often private insurance usually pays for less than 50% companies pays and any type of case management falls on the family, as most case managers generally perform the duty of "gate keeping."
- Everything takes too long
- Not getting approved for the needed equipment and the wait was almost a year
- Repairs take long or if we have multiple they will address only one approval for a foster takes too long
- Access and Insurance.
- Never got the new BP machine we needed! Finally had one given to us by a friend. Then tried again and had to buy it ourselves.
- Had to wait over a year for a walker.

If possible, please provide specific, real-life examples of when access to DME has been an issue.

- Getting repairs to a shower/commode is nonexistent, while waiting for demos of new equipment to come out to the home. It gets batted back and forth between CCS and the vendor, while the consumer/caregiver are told not to use the chair, which as I stated above is unacceptable.
- Every time I have to request DME through CCS or even services for patients at specialties I have been asked that it may not be a syndrome, never explained as to why it can't be a syndrome, and to send supporting documents. If I don't hear from CCS within a week I start playing phone tag until the assigned worker/nurse responds with a result or with a potential answer, but never a clear answer.
- When my child needed an electric wheelchair for independence they took parts away from her manual chair to modify the electric WC which made the manual one semi unusable.
- Yes, getting repairs to a shower/commode is nonexistent, while waiting for demos of new equipment to come out to the home. It gets batted back and forth between CCS and the vendor, while the consumer/caregiver are told not to use the chair, which as I stated above is unacceptable.
- 2 years to get a wheelchair, only to outgrow it before its arrival denial of transit package on wheelchair for a school age child riding a bus refuse to replace items (mattress, vent test lung) that had been provided in past wrong food/ equipment arriving on long term patient with standing orders supplementing name brand orders with generic wrong trach tubes arriving.
- None. I have all I need for my daughter. She has a wheelchair, walker, and afo's.
- One example was with my son's power wheelchair. It stopped working in December, we took it to the vendor right away. They didn't even start working on it until January, and it was fixed by end

of March. Only to have the same problem occur in April, which was fixed again in May, then broke again in June, fixed again in August, broke again in October. His main sense of independence comes from driving his power chair, yet it was out of service for the same issue 9 months over a 12 month period because of delays waiting authorizations for various steps of the repair process.

- For the first 10 years of my son's life, his Kaiser insurance did not cover DME. Now it seems that it does cover some.
- Jan 2017, was staffed with one DME, who delivered a shipment of oxygen, only to call the day before the next scheduled delivery to say that they would no longer be able to staff the oxygen as our home was too far away and they had transferred it to a different company. By 4pm on the day before delivery, we had no contact from the new DME. Our son had a full day of doctors' appointments the day of supposed delivery and we needed the tanks refilled to be able to attend.
- The process is difficult- many different steps, authorizations, clinics and appointments to get the equipment- coupled with Doctor and therapy appointments with a sick/fragile kid is almost too much.
- My child's last wheelchair. We waited and waited and then were told someone had lost the measurements. Had to re-measure and resubmit everything. When we received it, not everything was there, so more waiting.
- Ramp van for wheelchair: when our daughter got a new wheelchair Dec 2015, we began process of purchasing a ramp van. Regional Center process is not clear and provides insufficient and inaccurate info. Approval of complete application supposed to be within 10 days. Took nearly 2 months and RC insists that it will only cover manual ramp when the medical standard is automated ramp. AJ Hearings have supported my claim. Ramp van dealer, Access Options, dishonest in sales contract, lying, overcharging and misrepresenting sale contract, financing and vehicle options. The process takes unfair and undue advantage of children and families with disabilities that can only access the community with wheelchair vans. I think greater scrutiny of dealers/RC and support for consumers is overdue and in violation of the Lanterman Act and ADA.
- It is very hard to trial some equipment, such as power wheelchairs, so that our children can learn to use it so they can qualify for it. We were also told we had to be able to transport a power chair, so we took out a loan to purchase an accessible van so our child would qualify. (How unfair!) The kiddos can only use it at CCS and this makes it very difficult for them to learn all they need to know during the trial period. It is also impossible to find vendors for some of the prescribed equipment such as gait trainers, standing tables, etc. unless they are a certain brand vs. the brand that best fits the need of the specific child.
- We asked for non-bald wheels. They were supposed to deliver them and install them at CCS. They showed up without the parts. They promised to install them at school, but didn't make an appointment, and so the school denied access. They finally dropped them off at my house, but they didn't fit, so they're sitting in my garage. And my son is rolling around on bald wheels with brakes that don't really work.
- We've been at this for four years now. (Our son is four.) As a result we have gotten much better at getting out son what he needs. I wish that there had been a more thorough orientation from an advocate when we first began working with our Regional Center and CCS. It is pretty clear to me that the case managers have too many kids in their caseloads. It requires parents to case manage their case managers, and that is confusing and exhausting.
- My daughter's breaks have needed to be repaired since August 2016 on her wheelchair. Despite following up diligently, the parts have not arrived or if they have no one knows where they are...last week, I emailed Numtion saying if she has an accident I will hold them responsible.

- When I wanted to get a device that helped me carry my 13 year old child because she is getting super heavy they denied it so if it rains it is ok for her to get her butt wet?
- Working as a regional center caseworker, I feel like I've had to do a lot the work of the CCS case managers in contacting doctors, hospitals, vendors, etc. in order to ensure that prescriptions are sent, processed, denials are submitted, etc.
- Bathroom modifications, the time it takes to receive almost all strollers from clinic date to time of delivery, the van modification process in general is extremely inconvenient for all families who need this to transport their families in the community.
- It took over 5 months to get a needed piece of equipment.
- Currently, we were denied a replacement pair of AFO's for our daughter. We are only asking for a replacement pair because she has outgrown the current pair. It is extremely frustrating to be denied because she needs the AFO's for medical purposes, but also because of slow growth, the current pair has lasted 2 years, 4 months. The average lifespan is 9 months. We have no idea why this is a fight to get them covered, even though letters of medical necessity were submitted, and 3 doctors submitted evidence separately for why she needs them and they are still denied.
- We can access the vendor through our CCS unit, however, the vendor is slow to process requests and it takes months to get equipment. See #1 EVERY time we order anything - a screw, a back, a seat a break – months
- When my son had his pectus excavatum surgery at Stanford Children's. He was required to sleep sitting up as high as he could and lay still without moving his upper body. He was able to do this in the hospital with the correct bed. The doctors requested that he have this same type of bed for when we got home. He had a long recovery period.
- I was denied my initial request for DME, as my son was able to walk.
- A consumer who benefits from physical therapy but there is only one vendor available who is 45 minutes from the family but that is their only option. Family would like to explore additional kinds of therapy but it is not available. 2. I had a consumer who required a new bath chair and possible adjustments to his motorized chair. He was turning 21 and was told that as long as they could bill for the bath chair before he turned 22, they could provide the service. They did not bill and did not provide the service while he was still eligible for CCS.
- Child has been referred for vision therapy (was recommended by CCS), OT/PT, wheelchair, bath chair and has been denied.
- Bath chair too small and had a regional center assessment recommending new one. Chair was so small it was unsafe. CCS took a long time to come out and assess when requested and then had difficulty getting rx written correctly. Took 12 months to get the bath chair.
- Had to have brakes replaced, they sent two brakes for the same side, screws had to be replaced they sent the wrong size screws, Multiple times when not all parts were sent so multiple visits were necessary. One new wheelchair took 9 months to complete.
- Not access but seemed therapists and hospitals were pushing to place highest priced equipment when not needed.
- SAR requests may take weeks at times for approval.
- CCS did not think our child had the abilities to operate a power chair. They had provided a wheelchair, but he would be so fatigued rolling from class to class carrying all of his books. I kept

pushing, finally asked if we could borrow a power scooter. We went to Target; I videotaped - kiddo was in heaven exploring the music department independently.

- When we first wanted to get leg braces for our child, we found it impossible to find out if insurance would cover them or not and insurance refused to pre-authorize them. Nor would they deny them. We just had to order them and take the risk that we would have to pay for them ourselves.
- I requested a stander for my son and my request was denied. I filed an appeal. Took 8 months before my son received his stander. That is too long. Also med equipment vendor are only allowed to make home visits once a year. I have 2 teens who are CCS clients and each has several med equipment. I can only bring one at a time to CCS MTU for repair. We requested for an additional home visit and we were denied.
- Eventually, all equipment does for dinner it's way to my son. But the process is BROKEN. Yes, ccs in Madera is overworked, but really? Then I am told that they like to wait to process All DME for a specific client at one time. WHAT!!!
- They refused to authorize a "feeding/activity" chair for my son because he already had a wheelchair. My son was 8 year old and sitting in an unsafe, store bought high chair for a baby when he ate. We ended up getting a feeding chair through our regional center and by paying \$1200 out of pocket. Ridiculous. This is just one example of many.
- My daughter first wheelchair took 6 months her 2nd one is now at 4 months
- Waiting 6 months for equipment. Denied adaptive car seat for older child. Only able to get items from a certain company, so if they do t carry the item your child needs, you don't get it.
- My daughter's wheelchair needed some repairs and the seat belt ripped. I sowed the belt because she was not going to be allowed in the bus for safety reasons. I called and told CCS, everything was addressed except the belt. I had to sow it 3 times already. Also for her braces, request was submitted in December 2016 by doctors, I called, emailed, is February and nothing still waiting. In the meantime no Afos, which means all surgeries done are going down the drain because no Afos to keep her foot straight.
- After a bunch of phone calls and phone tag we were told that we needed a prescription for a new blood pressure machine even though our daughter had been given one when we brought her home from the hospital through ccs and we were just replacing it due to it starting to malfunction and give us bad readings. By the time we finally got in to see our doctor who is booked out quite a while and got the prescription it has been months since our original request for a new machine and we had had to find one ourselves. Then when her needs changed again we had to try again and again we bought our own.
- Notified CCS and National Seating and Mobility that walker was broken in December 2015. It wasn't until June 2016 that a walker was finally delivered.

Has your child ever had to remain in the hospital because he/she was waiting for a specific piece of DME? Please describe.

- Not sure as I am a referring provider and assist patients receive their DME. I haven't known of any such encounter.
- Wheelchair modification due to surgical procedures wrong trach tubes
- Yes. Had to wait 2 additional days to bring our son home from the hospital after open heart surgery due to a feeding pump not being available to deliver.

- No, but primary insurance paid for everything (not Medi-Cal).
- Not exactly but had to be transported home by ambulance for same reason. Wheelchair modification was unduly delayed. Took nearly 3' mos!
- Not yet, but there is a surgery scheduled next month so we shall see.
- Yes when she had a spinal fusion we needed a device to help her up the stairs we had to move in with my aunt because they denied it.
- In this particular case where my consumer was awaiting a hospital bed to be provided by CCS, my consumer's mother had to lay with him all night to ensure that he did not fall out of bed and injure himself upon having his regular seizures. Additionally, the consumer has respiratory and G-Tube issues, so he needed to be sleeping at an incline--which was very difficult without the hospital bed.
- Yes, insurance went back and forth on who was going to fund the oxygen system, portable tanks, and even then, the portables are not enough to make it to a doctor appointment and back!
- Our child has had to be hospitalized multiple times and is not improving and not having equipment on a timely fashion or adequate therapy contributes.
- No, we received the DME from doctor request - hospital bed - from an approved vendor through primary insurance. It's when we have to use Medi-Cal (our secondary) that it takes forever - add that to vendors who aren't well versed in equipment repair and/or sizing - incorrect parts get ordered, they don't fit, we have to start over. When "clinics" are held once a month in the CCS units, you are stuck until the next month that an appointment is available.
- No. We went home without the bed in place
- No, but I would have bought it myself if that were an issue. That is unacceptable to me.
- She has never been left waiting in the hospital but there was concerned about the small size of her wheelchair and her car seat was way too small for her size. Most hospitals will not care about the state of DME equipment versus the amount a bed space would provide.
- Only briefly when the wrong wheelchair was delivered.
- Almost, however because I am such an advocate and can speak as a healthcare provider this has not happened. However a day without a wheelchair means my son will be lying flat on his back in bed.
- Yes, about 3 years ago. It was faster got the Afos in 3 days.
- Yes. When we were bringing her home at 2wks old we had a 13 hour delay and had to run all over San Jose to get her BP machine from the ccs provider...then it was the wrong one according to LPCH staff so we had to go back and pay out of pocket for the smaller cuff that LPCH required us to have before we left the hospital. CCS told us that that cuff would not work for her and that was not true it was the only cuff that would work for her for the first eight months of her life.

Outside of a hospital setting, have you ever had to wait an extended period of time for DME? How long? Please describe.

- Yes, first I was asked to bring the shower chair to the MTU??? That appointment alone took several weeks to get. At that appointment it was agreed that a new piece of equipment was needed in addition to repairs to the existing chair. We started this process In late 2015 There have been so

many issues, most of them were with the vendor not providing the demos, repairs, then when the equipment was ordered, and delivered, the specifications to the chair were never made, which set off many more months of problems resulting in canceling the order, and changing vendors. The process of ordering the equipment had to begin all over again. There are many problems with the current vendors, but I also find fault with the OT at CCS for a complete lack of follow through.

- For DME yes, not necessarily through CCS. A couple months.
- Two weeks.
- Over two years for a wheel chair over a year for a mattress 4 months for custom trach tubes
- Very frequently. It usually takes between 6 and 9 months to get a new wheelchair. 4-6 months for a walker or other piece of equipment. CCS MTUs only have one day a month where they deliver DME. If you can't make the day, you have to wait a month.
- Yes. Weeks/month for replacement AFOs, week+ for wheelchair repair.
- 4 months to wait for a wheelchair. 4 months to wait for a posterior roller. We borrowed one from his physical therapist. DME delivered posterior roller walker the same week he independently walked. Had we not had the luxury of a loner walker he would not have learned.
- Took about 6 months to get her 1st wheelchair and stander.
- We usually wait 8 weeks or more for equipment or parts to arrive.
- Yes: stander, afo's, wheelchair, ramp, shower chair, wc repairs and adjustments, replacement head support. Many of these are available at manufacturer, but CCS and vendor/service provider slow process down. Should be high priority and prompt always!
- Yes, over a year. Because our private insurance won't provide a letter of denial unless the equipment is first purchased. And CCS won't ok a purchase until the private insurance provides a denial letter. So if we were poor and didn't have insurance, we might already have the stander that we started pursuing over a year ago.
- We are still waiting. It's not going to happen unless I find another vendor, I guess.
- I feel like all equipment takes anywhere from 6 month to a year to receive.
- I have waited for things for a year!
- We waited 6 months for a stander. We never received it because the request was closed.
- Yes never got it to this day.
- Over two and half years.
- Almost 2 years!! The estimates were not coming in, when they did come in, they apparently did not match the recommendations, obtaining estimate revisions took even longer. The process is held up if only one estimate is submitted and correct.
- Yes too long 4 months or longer. They need to have a greater urgency and real time requirements.
- Yes - went for an appointment to check AFO's 2 months ago and still waiting on an approval. So my daughter is wearing unsuitable, ill-fitting AFO's while this is being sorted out.

- The longest we have ever had to wait for an entirely new wheelchair was one year. The second longest was for replacement parts for a chair after a surgery - 10 months.
- We were not given the opportunity to have the correct hospital bed or shower chair after his surgery.
- Doesn't qualify for DME.
- Yes, for a walker. We waited months.
- Yes, weeks.
- Power chair - still waiting. From pushing for a trial with power mobility, waiting for denial from private insurance, trialing different power chairs to finally receiving power chair only to realize we were issued the wrong chair without the features we paid for out of pocket - (iLevel and Bluetooth features)
- AFOs can take up to 6-8 weeks after fitting, so he has to endure ill-fitting old AFOs. Walkers and wheelchairs take an average of 3 months to get after fitting.
- We decided to take the risk that we would have to cover the expense ourselves rather than wait and delay mobility and gross motor development.
- Yes. We waited nearly 6 months for a pediatric walker over the example shared in question one.
- I requested a stander for my son and my request was denied. I filed an appeal. Took 8 months before my son received his stander. That is too long. Also med equipment vendor are only allowed to make home visits once a year. I have 2 teens who are CCS clients and each has several med equipment. I can only bring one at a time to CCS MTU for repair. We requested for an additional home visit and we were denied.
- Months on new forearm crutches, months on wheelchairs, months on walkers. And you would think that donating back a \$6,000 piece of equipment to CCS that my son out grew, would Balance something out.
- Yes. 6 mos - a year for medical equipment to come in. Been refused for many things too.
- Longest is 6 months
- Yes. 6 months for a pushchair and 12 months for a power chair
- Yes, months more than 2.
- 2-3 weeks.
- We are still technically waiting for a new blood pressure machine from CCS. Our daughter is 3 years old now and we asked for it when she was just a months old.
- Yes. 6 months for a walker. Delay due mostly to National Seating and Mobility.

How have delays in getting DME impacted your child?

- It has impacted his safety and quality of life. He has fallen out of the unrepaired chair. He has no lateral side supports. He currently is in need of a seat pad for pressure relief, but I'm told it can't be ordered until the new chair has been ordered, processed, and approved.

- Pressure sores due to out grown equipment loss of skill due to not getting equipment use old or out of date equipment.
- They affected her independence because she would need someone to push her around in a wheelchair.
- Sometimes he's had to go without an AFO or with a duct taped AFO. It did not severely impact his mobility.
- It took away his independence for 9 months out of a year. Which has negative effects on him and he also lost strength in his hands/arms so he permanently is less able to drive. Delays in fixing or obtains equipment frequently causes loss of strength or function that is permanent. Due to his condition, he does not have the ability to regain skills once they are lost due to lack of use.
- My son can't walk without his AFOs, so he had to wear broken AFOs that were held together with duct tape while we waited for replacements.
- Right now we need a new wheelchair and have been to CCS twice -- I now have a denial letter from the primary insurance which is what I was told that we need, but I'm not sure what comes next. Our primary insurance should actually cover the chair and Medi-Cal fill in after so I'm not sure why they wanted a denial. I need to look into things further.
- I've had to keep my child out of school while her chair was worked on and it was wrong so had to reorder. This had happened more than once.
- Currently, my daughter had major surgery on 1/24/17. Her Wheelchair modifications were requested from CCS prior to surgery and I continually called. A months later, 2/23/17, the part (elevating leg extension) will finally be installed next week. Just understand, the parts have always been available from manufacturer, and ship in 2 days, but bureaucratic process took 2 months! Typical and faster than usual. 12 year old can't leave home!
- Power chair, standing table, and soon, a lift for transfers.
- Unsafe brakes. I'd like him to have wijits, but the vendor is unable or unwilling to do it. Can't tell which, but it leaves my son much more dependent, and less active.
- All delays are problematic. He is a young child. When he is unable to access his space, or have assisted devices he basically is just "on hold" developmentally. His cognitive abilities are strong, so it is frustrating to see his growth stalled.
- She maneuvers a wheelchair that is not well maintained, and then is asked to propel herself, when the wheelchair tires are used, the wheels are not rotating properly.
- Our child does not have access to important equipment through these key developmental and growth stages, greatly limiting her opportunities to develop and build strength.
- She still has to go up the stairs on her butt. When it rains I have to have someone carry her up.
- This child's health diagnoses and lack of appropriate DME (i.e. hospital bed) created an undue risk of hospitalization and/or death.
- Access to necessary follow up appointments with specialists at UCSF, UC Davis have been prolonged and care was not able to be provided due to lack of sufficient DME.
- More hospitalizations.

- My daughter currently has developed sores on areas of her feet where current AFO's do not fit any longer. They have been adjusted as best they can but she needs a new pair.
- My daughter had spinal fusion surgery three years ago. The back on her chair was inappropriate for her "new back" - it took us over 10 months to get a replacement. We have gone through 3 different backs that were inappropriate for her needs before we changed vendors and got a new, appropriate back. She lives in her chair - having an uncomfortable back impacts her every day, every minute.
- I had to be with my son 24/7 while he recovered making things up as we went along. No support or help was offered or given when I told them what we needed and the urgency of the request. I had the paperwork from the hospital. The things the surgeon recommended be in place for after the surgery. And his local doctors request. Nothing was provided and I was given the runaround when I tried for several weeks after we came home to get the bed he needed.
- We were not able to take my son out in public - due to his meltdowns and tendency to attack, hurt, head-butt us.
- Child has had to go through regional center clinic for wheelchair, school for OT/PT (which school is only provided OT at this time).
- Unsafe to bath, hard on care givers back which can effect caring for them later.
- Not having the walker meant no mobility. Incorrect wheelchair meant she was not in a safe piece of equipment.
- Unable to start timely medications for newly diagnosed CF patients.
- Our child cannot easily access his community and school. His batteries in current chair are unreliable in holding a charge; every 3 hours needs to charge his chair. He cannot go out in community for an extended amounts of time.
- Many times my child was sick from the draft on the floor laying on the mattress. Also she would roll over onto the floor and her Gtube would be yanked out of her stomach. This was from the lack of hospital bed. Also she would get bad acid reflux from being un-elevated on the floor even though we had pillows. Not having a safe way of transporting her upstairs resulted in me dropping her several times from several falls. I believe waiting on a larger wheelchair caused her lots of physical pain being crunched in being hunched position. In fact after being in small wheelchair for so long I believe it led to scoliosis.
- Having to make do with ill-fitting and/or failing equipment.
- We decided to take the risk that we would have to cover the expense ourselves rather than wait and delay mobility and gross motor development.
- Physical development outside of therapy sessions at home and in the community were drastically delayed.
- My teens were not able to take a shower on a daily basis because their shower chair was not at the same height as their wheelchair for easy transfer. My son was has been sitting in poor posture in his manual since he has outgrown his chair. He has airway obstruction and has curvature of his spine. My daughter is not able to use her power chair while waiting for repair. She had to use her manual chair which makes her more dependent on me.

- Safety primarily. Walkers that have poor design and with my research, I find one more stable. Crutches... also safety. I had to purchase the last set because there was no padding on the cuffs.
- "You can't have a kid walk until your chair can take x amount of step." How is my child supposed to learn to take step when he can't practice? Delays and rejections curb my child's development.
- It means that he would not be able to leave our home or his bed.
- Quite a bit since she cannot walk.
- He had to be carried everywhere and not able to have access to his community.
- Her surgeries, she went through all the pain for it not to be reinforced because of approvals are not done in a timely manner or because is not time. I would not be asking for repairs or Afos is she didn't need it. Ridiculous that it could only be fixed or get parts so many times in a year or years. They are kids and things wear out or get outgrown.
- Limits independence.
- We have made sure they haven't.
- My child had to use a walker that was too small for her causing back and arm pain.

As a parent/caregiver, how does time spent dealing with DME delays impact the care of your child?

- My child requires full-time care, and the time spent on the many phone calls to CCS and vendors, limits some of that time.
- More that I can count.
- Extra work having to push her around.
- Having to deal with phone calls, follow-up visits, transporting equipment causes loss of work time, loss of quality time with child, anxiety and stress in caregiver.
- DME is one of the many time-consuming aspects of raising a child with special needs. When I am on the phone or computer working out services and issues, I cannot attend to my kids.
- Many hours on the phone each month takes away from interaction and bonding time with our son.
- Her safety and comfort are compromised when the wheelchair is too small and needs replacing. She misses out on the therapeutic effects of using the stander when we don't have one that fits. Right now we had to rig a chair in the shower to be able to bathe her - not super comfortable or ultimately safe (although we have made it safe).
- When they have to keep her chair, she cannot be transported to school or doctor visits. I would have to call an ambulance if she got sick.
- I work full time and a lot of my lunches and breaks are spent calling them. My daughter cannot participate in the community if appropriate mobility equipment is not available and delivered/provided and repaired in a reasonable amount of time.

- For the power chair, our child had to wait a year until she could pass the 'test' due to trialing in an adult chair vs. a pediatric chair and only being able to practice for the 40 minutes of therapy time. So our child was DEPENDENT instead of independent for longer than reasonable time. For the stander, it impacts her ability to work on bearing weight daily, and so she is weak and we have to do more lifting than active transfers. This is wearing on our backs and for her health, there are long term impacts (brittle bone, respiratory problems, etc.) She needs assistance transferring from chair to toilet to bed to etc. We are carrying her. She is getting older and bigger. Sometimes there is only one caregiver at home. It is a hazard to our health (backs) and to her health (what if we trip or fall while transferring her?). We were told we should get a Hoyer lift (affordable), but she doesn't need to wear diapers except for overnight, and the Hoyer is for people who wear diapers. The other lifts are too expensive and the vendors won't order them because of reimbursement is low. We don't want to lower her quality of life (embarrassing to wear a diaper all the time) and compromise her health (diaper rash, skin breakdown) nor her emotional health (a teen should not be carried like that for toileting, it is humiliating and disrespectful to her at this age). So we are most concerned with the impact on our child's health, and our health is secondary a concern too. And now it is difficult to get a nurse because of lifting without the proper DME!
- Mostly, it interferes with my work.
- Our wait for his wheelchair made it so that we could not purchase an ADA Van for quite some time. This led to us having to carry him in and out of our small family car. This became very difficult on our bodies.
- I get stressed and that impacts our entire family and my health. I also have to take off from work, or not work. My employer has a hard time believing I am doing all these trips for a piece of equipment!
- I already have many demands on my time with appointments and managing prescriptions. DME challenges add yet another barrier to being able to spend my time on direct care.
- It impacts it a lot we have to deal with a lot already and to have to prove and explain why she needs the equipment when you already know her diagnosis is disturbing.
- It impacts their health, safety, and family's livelihood.
- Adequate care is unable to be provided, conditions have been worsened by the inaccessibility to travel to needed doctor appointments when scheduled or even rescheduled.
- It impacts me greatly and leads to frustration and stress. Not once has a CCS person said "I'm here to help make things easier, happy to help." I have heard that from vendors which eases my burden.
- Time spent having to deal with the system in general creates a huge amount of frustration. Because the mentality is to deny everything, I have spent months fighting for things that she needs. Because of this, she uses equipment that she has grown out of or doesn't fit any longer that causes her further problems, some that will be difficult to reverse (for example, sores on her feet from AFO's that are too small and a continually escalating scoliosis curve due to denial of appropriate seating system). 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.
- The time I spend on the phone, following up on authorizations or prescriptions, taking her to "sizing" appointments and follow up appointments - all of it- takes a coordinated effort to keep track of everything and takes up my limited free time.
- As his caregiver I was impacted with limited sleep. As a heart patient I was also bed ridden at a time during my son's healing and my daughter had to take time off and help us both. Because I had

to make sure he didn't dislodge the bars in his chest cavity by accidentally turning wrong or sleeping prone. He had to sleep sitting up as high as possible and he needed pillows supporting him. He could not lift his arms or have them above his head. It was scary for both of us. When he was in the hospital I was shown how to adjust his bed to support him and to make corrections for his scoliosis as well. He was able to sleep in the hospital and I was able to sleep as well. Not when we got home.

- I will tell you, life was so much easier after the wheelchair with restraint was in place.
- Not able to access community due to waiting for equipment.
- It is stressful and time consuming. Case managers seem not to help at all. Regional Center staff have to assist in order to get equipment and a response.
- It means less time to deal with other issues and enjoy time with my child.
- It is exhausting to keep track of what is needed, what works and what does not and then figure out what out of pockets, insurance coverage will be.
- I am a pharmacist who spends much time trying to get DME covered for my CF patients. It takes away time that I can better spend on patient consultation and education.
- Very stressful, filing grievances with private insurance. Taking time off work to be there to trial, make determinations of features, secure medical necessity from primary care physician and receive equipment to insure it is equipment that was originally ordered.
- It's time I can't be with her and I have to use my free time to contact doctors, therapist, and writing letters. Researching the law on what is the rule of DME equipment. I spent more time building a case that was unnecessary stress. When I'm spending years trying to get equipment my child's feedings can be delayed, her needs are not being met, my other children are not being cared for, I have to pay sitters to watch my children why I spend time making phone calls, researching DME requirements, and writing letters. Many times I have to talk with her school about her equipment not meeting her needs.
- The process is excruciating and trying, and often forces us to come up with temporary solutions to get him through.
- Just adds to financial stress of parents and negatively effects their health. I work around the clock to support my daughter. Our primary private insurance has always paid in the end but will never verify beforehand. We delayed 30 days and were able to locate a company who was able to bill Medi-Cal but they could not order for us because they said they "did not make enough" on the item for it to be worth it
- It's like a part-time job to have to deal with DME needs.
- Many calls to MTU office staff, therapists, vendor and supervisor to get authorization for service and coordinate a time for appointment. High stress, frustration, time consuming, taking away for the care of my teens.
- 100% I should be paid for my time and energy.
- Curbing development and in certain cases can make general care much more difficult. Delays with bathing chairs for example and other equipment can make life hard when doing every day card.

- It means I have to take time off of my job and or pay for a caregiver out of pocket to support meeting with DME providers
- Significant.
- They are left out of daily life activities causing emotional distress
- Yes, it upsets me that I cannot get things that my child needs.
- We just make up the difference so she gets what she needs.
- It is extremely frustrating. This is on top of coordinating payment from Kaiser and Medi-cal.

Have you ever paid for DME out of pocket when you felt it should have been covered by another party? Please describe.

- Even though this is not durable medical equipment: We pay out of pocket for pull-ups that "fit" as the quality of pull-ups the Medi-Cal provider offers do not fit resulting in leaking at legs, and soiling clothes and wheelchair cushion on a daily basis. In addition, another area as a result of the CP is dysphasia/aspiration for which we have to purchase thickener to thicken all liquids; this also is paid out-of-pocket and is a very costly expense.
- I have had to purchase items in order to get them because the process of getting them replaced in a timely fashion has not worked.
- Not completely out of pocket, but our percentage is still pretty big.
- Yes, I have purchased walkers, standers, arm lifts, communication devices, and even medical equipment like pullseoximeters, inessfulators. I once had to purchase a \$1,500 prescription drug because CCS did not cover it the first time it was ordered by the doctor.
- Yes, for wheelchair repair. The vendor was out of town and my son's wheelchair frame cracked. I paid for a local repair person to come to our house.
- Yes. We paid for a portable oxygen concentrator and batteries out of pocket because the insurance company decided that it wasn't medically necessary to use for a flight, even though he was on continuous oxygen.
- Yes, communication equipment and a Convoid Rodeo wheelchair because it is far more comfortable, lightweight, and affordable than the wheelchair that we were told is the only option Medi-Cal will cover.
- Yes. Wheel lock for wheelchair oem cost \$32, got in two days. DME vendor took over a month.
- Yes. Her first toilet chair. We are now considering another piece of equipment, a transfer lift, because we don't want to compromise her or our health and well-being.
- Yes. We will have to buy the wijits ourselves, by mail order, and try to adapt the chair to use them. Our vendor (ATG) should be able and willing to do this, but they're not.
- Yes, I have ordered covers for my daughter's back and seat, when the ones she had were so used up I was ashamed of her sitting on them.
- Yes. I have she needed a new walker because it was stolen from my car among other items

- I considered attempting to get it through different organizations that have DME donated to them. We actually had it coordinated to have one delivered to the family, but CCS finally came through (2 and a half years later).
- No. Cannot afford. Child and family suffer.
- Yes, we needed a seatime cover that was washable for hygiene needs.
- Yes - we were strung along for 9 months for a SGD with promises that the copay would be picked up by Medi-Cal and that never materialized. After 9 months, we were so frustrated that we paid \$2500.00 copay ourselves.
- I have purchased a folding wheelchair and a gait trainer. We get one wheelchair every 5-7 years - our wheelchairs need to be fixed chairs for use on the school bus and in our vehicle. But sometimes a portable chair is more feasible for travel, school trips, etc. A portable chair isn't necessary because the fixed or primary chair is already purchased.
- I had no money to get the DME in my home for my son. I was told that California Children's Services was responsible for the DME. My son never received the medically needed equipment
- Vision therapy
- Yes, all the time.
- Yes, many of my patients paid for DME in lieu of waiting.
- Yes - insurance, CCS did not think that having a chair that can raise up to counters, rise up to help with navigation on busy crowded streets and train platforms, rise up to retrieve household items was not medically necessary; they prefer my child be low and restricted and unable to access his community. We paid out of pocket for iLevel and never received iLevel. Currently being remedied. 2 years out from pushing for power mobility
- Yes! The dreaded hospital bed and safety rails padding. Before her activity chair was approved I had to buy high chairs and try to modify it with no avail she was extremely too large for a high chair. Any solutions I had for DME equipment was ignorant a shot in the dark due my lack of knowledge of disabilities and what a child in her situation would need. It has been many trials and error and finding out how to make her life accessible and livable.
- Yes. We have bought a set of crutches and a walker that would have been covered as the timeline was just too long to wait.
- We had to be willing to take that risk.
- Yes, sometimes after a CCS denial I pay out of pocket depending on the urgency of the need and the cost
- Yes because I couldn't get anyone to move fast enough
- Yes. CCS will deny then you go to regional center who usually only pays a portion and insurance will deny as well. Things that are not a luxury but a NECESSARY part of daily living for my son have to be paid thousands of dollars out of pocket. It's infuriating.
- Yes, her sleep safe bed.
- Yes. Bathroom chair, bars, ramps, adaptive car seat they all were recommended by multiple physicians and had prescriptions and were told they would take months to even find out if CCS would approve.

- No, but I wished I had the money instead of waiting but I have no choice.
- Yes Ped Walker. Just bought on Amazon because no one could help/confirm coverage.
- Yes. 3 blood pressure machines, a stethoscope and a neonatal cuff.
- Yes. I was told my Kaiser that Medi-Cal denied a claim and I was responsible. I didn't have the time or energy to determine why.

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.

- Yes that is definitely a part of it, as well. Another factor is having to wait 1 to 2 months to get an appointment for the wheelchair clinic to make decisions about equipment.
- YES!! This is a big problem. The wait is always on who is going to take on payment. First CCS states they need for patient to request through a managed care plan and if it gets denied then they want the letter from managed care plan and vice versa. Its a game of tug and war and its extremely frustrating.
- Of course neither government nor private insurances want to pay and each one has their own rules.
- Yes, there are three (and sometimes 4 payers involved for certain equipment. We have employer provided private insurance, Medi-Cal (CalOptima Community Network), CCS as insurance providers. Also, some equipment can be funded by the school district as well.
- Yes. The process has involved me getting a prescription from my son's doctor, him sending the prescription to the DME office, waiting for them to send a denial letter, sending that letter and the prescription to CCS, who then set up appointments with vendors and worked with Medi-cal. The process takes weeks/months each time.
- I believe that a big portion of time is spent with insurance companies trying to deflect payment, with pre approvals and medical necessity reviews.
- Yes sometimes. More often it is b/c of initial denial that when followed up with a challenge is then overturned and the equipment gets approved.
- Yes, does CCS pay or do we bill Medi-Cal or do we have to wait for a rejection letter from one company before we can order from another?
- Yes RC and CCS. We also have Anthem
- YES!!! As stated above, having to get that denial letter from private insurance has made it impossible to get some equipment. It's a vicious circle. CCS won't cover it without the denial letter, and unless it is purchased, private insurance won't give a denial (or approval) letter. And our child is stuck in the middle doing without!
- It has caused insurance issues because the billing is so late. Sometimes (in the case of the wheels) they bill for equipment that was never installed.
- Yes. This is usually where all the delays live. It takes so long to get approved for funding because of the necessity to be denied by private insurance, and then by the school district, and then by

CCS, finally to be covered by our Regional Center. We can be stuck going in circles for endless months. We are experiencing that with his AAC device presently.

- I don't know about why the delays happen. I feel like a ping pong ball with people pointing at each other.
- Yes, at times the information that one party (e.g., physician) needs to send is not always clear, and so incorrect paperwork creates huge delays because the doctor's office thinks it's already been done.
- Yes always goes to private and then Med-Cal and then CCS decides it is really bad
- Yes, this is part of it. It's also dependent on workers not following up on prescriptions or recommendations. There seems to be no accountability or timelines for following through on processes or ensuring that things get done.
- Yes. Insurances, especially if double coverage continually state the other is responsible for funding. Neither agree to fund. Child and family suffer.
- I believe the MTUnited has many excuse from therapists only working so many days and then they can't get vendor. Our therapists are traveling from two different units and are only there one to three days a week.
- Yes, always - the number of steps it takes - from primary doctor to CCS, to primary insurance to secondary, and on and on. If one person writes down the wrong part number or the wrong request, everything gets messed up. It should be easier.
- Of course it was due to the decision of others. Both CCC and Medi-Cal delayed the decision and even told me that I never requested the DME that his surgeon said he needed! His doctor also submitted the request.
- Yes and regional center generally has to pay due to now qualifying for DME.
- This process takes way too long. It may be months before denials are submitted and then given to regional center to consider. Denials at times are for lack of rx specifics. It would be prudent for CCS to call doctors and ask them to rewrite rx instead of expecting parents to do it. Doctor changes one word and then months later, item can then be paid for.
- Yes, when people do not talk to each other about who is paying.
- Yes we are stuck waiting for denials from our private insurance, the private insurance delay and drag out the process, requesting more information upon more information, as months tick away.
- DME equipment time has always resulted in if the equipment is needed, getting the necessary CCS doctor prescription, and then making sure it's not a duplicate of equipment. If CCS did not approve a DME it was later funded by regional center.
- Yes. There is a constant conversation between them about who else could fund things and vying to be the payer of last resort. There is also often misinformation from the various parties that could cause things to get dropped.
- Yes. The problem was we could not get preauthorization and it was not clear who would pay. Our primary insurance (Cigna) also will not respond to a "bill for denial" or any other form of denial acceptable to Medi-Cal, so we also can't get Medi-Cal to pay for our diapers. We have to pay for them ourselves. I spent more than 1 year and 10 phone calls trying to sort this out before I gave up.

- Yes, CCS SARS usually takes weeks, sometimes instead of a denial, we get seemingly endless questions to delay the process. Sometimes the request is approved when the same questions are asked over and over again over a period of time to wear us down
- No. We all know who pays. It falls with not enough staff and also with people that just flat out cannot do their jobs. My last question to them was...do you have some antiquated system that allows for holes, no schedule or follow up? Are you operating from a white board??
- Delays are every step of the way. Paperwork takes time, approval of disapproval takes time, orders take time, and fittings take time. It's not uncommon to wait over a year for DME
- Often our insurance would pay for equipment that was substandard and not appropriate. Therefore Medi-Cal would deny it because private insurance would pay for it.
- 110% related to time and knowledge of the diagnosis.
- I guess yes, CCS, when they approve and pay
- Delays in getting authorization are usually minimal.

Please outline possible solutions to the DME problems you've encountered.

- Offer individual appointments to assess needed equipment immediately. Follow through with vendors providing equipment/repairs, instead of passing that off to the parent. It seems that no one is responsible, and the consumer/parents are left waiting.
- Have a report with the vendors so it makes it easy for clinic or provider office to request DME without any issues
- Updated guidelines for patients with disabilities that reflect the new century allow items already purchased to be repurchased better communication between vendors doctors having more say that DME providers in products
- Timelier and better coordination between case managers. Clearer policies about which payer is responsible. Consistent rules between payers.
- Just take care of the patients' needs for independence.
- There is no warning when an AFO breaks and you need a new one. We just have to wait for an appointment and then wait to have it repaired or replaced.
- I really don't know... other than minimizing the number of hoops parents have to jump through somehow.
- Once it is determined that a child has a particular condition, there should be an automatic pre approval list of the most commonly used or needed medical equipment items that is lifelong for the patient
- More staffing might help so one person is not trying to do everything. When a piece of DME is needed it needs to get to the client quickly so there needs to be a staff in place to streamline billing and insurance issues.
- Ombudsman and consumer council

- If a child/client needs a specific kind of equipment because of medical needs, then the reimbursement should be commensurate with what the vendors have to pay for the equipment. If we can't find a vendor, then the equipment can't get ordered. If there is private insurance and they refuse to give an acceptance or denial letter until the equipment is purchased, and CCS knows they will purchase it because the kid needs it, then they should upfront the purchase so that the required denial or acceptance of funding can take place. The kid shouldn't be placed in the middle of these crazy 'rules'.
- I have no idea why people being compensated are so reluctant and incompetent. Other vendors would help create competition, but ATG has bought everybody.
- Streamlined funding and communications between the various agencies and providers.
- Have one person be my contact person. Have this person return messages, give us parents the power to track where things are in the "system". give incentives when things are done timely and correctly. Treat our kids like they are Obama's or now Trump's kids!!!
- DME caseworkers or increased DME training for CCS caseworkers, complex care staff, etc.
- MORE UNDERSTANDING our kids need this equipment for EVERYDAY living.
- There should be more mandated policies for organizations to have to follow through on DME prescription orders, recommendations, requests, etc.
- Clear guidelines on funding responsibilities and adequate vendors/resources to provide appropriate equipment and services.
- One the therapists need to learn how to collaborate and coordinate. They need to learn how and to work with families with complex needs, anticipate, plan and accommodate all! We are having major scheduling issues as the therapist doesn't coordinate till the last minute
- STOP DENYING EVERYTHING RIGHT OFF THE BAT. IF IT IS BEING REQUESTED, IT IS NECESSARY EQUIPMENT. 2. We feel that the therapists that we have dealt with at the Vista MTU have been poorly trained. The PT and OT we had for our daughter gave up on her immediately because of her diagnosis. The PT actually had the nerve to tell us "Due to her diagnosis, she will never do anything. She just needs to be maintained." Because of the negative attitude, we chose to take our daughter to private pay therapy outside CCS and then we're accused of double dipping. We were not - we are paying out of pocket for her to go somewhere where they actually believe in her - and where she has made a tremendous amount of progress, no thanks to the CCS therapists that we left over 2 years ago.
- More frequent appointment availability to size for equipment - fewer steps in accessing Medi-Cal - more approved vendors -better trained vendors - more equipment options fully updated medical records that include notes on DME A DME specialist at Medi-Cal/ CCS/Regional Center - a case manager sort who can assist in figuring out who is working on issues for the family.
- How about less bureaucracy and more patient care!
- Possible loan program - as parents, we know what our children need, or items that would greatly improve the quality of life. I don't think I know of a parent of a child with special needs that would fabricate the need for this type of equipment, waiting on approval - is ridiculous, if it is an obvious known need.
- Quicker follow up and follow through to requests for equipment.

- Reevaluate cases to see who may need to qualify for DME, OT, PT, vision therapy and other services.
- Actual case management, training for physicians or standard CCS forms that doctors can check box the "required wording", accept assessment from regional center assessor who is CCS paneled so the process is not delayed.
- The reimbursement rates are terrible, companies are overwhelmed, too many agencies involved.
- Audit costs for equipment purchased out of pocket and price to insurance company
- I believe if the decision maker are better educated about the needs of CF patient then they can allow more DME to be covered. Also staffing shortage may be a possible factor to the delay in approval.
- Skip private insurance - they have no intention of funding DME; they go thru the motions but they ultimately deny the request. Listen to the families they know their children, their needs.
- Any medical doctor should be able to prescribe DME equipment. Education to MTUs on equipment processing, education to parents possible workshops on how to care for your disable child and the possible equipment needed and how they can be rapidly be approved. Such as bath chairs, wheelchair, activity chair, stander, hospital bed, rails, padding, stair lifts, hoier lifts assisted Walker's, specialized stroller, communication devices, feeding machines and their accessories etc. pole, cords bags, suction machines and their accessories olive tips nasal piping. All of these I have mentioned I have in my home and we use and it has been very difficult and frustrating to obtain.
- The families shouldn't be involved in the payee negotiations—the agencies and companies should be following a clear, set policy overseen by a state or federal agency.
- Single payer system. Or Make Medi-Cal pick up the copays and any denials from the primary insurance policy as a matter of policy. Or make them answer whether sometime is covered BEFORE services are rendered.
- Speedy decision within a week, clearly shows denial or approval so we can file an appeal or approach another service agency for assistance
- Hire more TRAINED PEOPLE, have a check system in place other than what is currently being used to follow progress of equipment. Do not let CCS hire equipment suppliers that they think they have a good relationship with that cannot do their jobs. Research other vendors!! I have as much trouble with NSM as I do with CCS equally.
- Don't base approval on what we already have but on if the equipment is a necessity for everyday living. Most special needs families are not requesting feeding chairs, bathing chairs, wheelchairs because it's a luxury but rather because it's a necessity and our families deserve to have the proper equipment to fulfill daily activities in a safe and effective way.
- Comprehensive case coordination. Not gatekeepers for private versus public fully funded healthcare coverage
- Quicker response and less red tape
- Allow our own team to make the decision on a case by case need
- Hire more workers to make the case load smaller.
- More vendors of DME willing to bill Medi-Cal.

Please feel free to add anything else you feel the DHCS should be aware about concerning DME.

- If there is a child who has a special need, for example CP, patient should automatically get fitted for a wheelchair. I have heard of children receiving inappropriate wheelchairs that have caused for the child to be hurt/wounded and parents have tried to fight in getting child appropriate chair and just stick with it as it's all they have for the moment.
- Pay for quality products not the cheapest because it will cost longer in the long term.
- We've had to put a handrail in the shower for safety, but we paid for it out of pocket. Is that something we could have been reimbursed for?
- Many DME rules are archaic and do not reflect the needs of today's mobile people with disabilities budget cuts over people's needs.
- Certain things that are for the safety of the child and/or care-giver are not covered but should be. For instance, for a Power Wheelchair, CCS does not cover an attendant control. However, there are situations where an attendant control is necessary even when the child is capable of driving on their own. For instance, school bus drivers typically are required to have control of the chair when they are loading the child onto a school bus. Without attendant control, the bus driver has to disengage the motor, manually push the chair onto the lift and into the bus. Secondly, there are times when the child is either sick or just not feeling well due to their condition. In these cases, it can be very useful for the care giver to take over control.
- My kid needs a wheelchair with full supports. Our only option is a very heavy, too large to transport super expensive custom chair that costs between \$15k-\$20k. I have asked for and been repeatedly denied a Convoid Rodeo: tilt in space, fully supported, lightweight (can fit in our car), costs only \$7k. We have been repeatedly told that it was an unacceptable chair b/c of support - yet we have used one (we won in a raffle) for 5 years that had the same supports and was much more comfortable than the chair we ultimately got. Given that this chair is equally supportive, more lightweight and manageable, and cheaper how is it that Medi-Cal will not approve it when it is what the family is saying would work best.
- Lanterman Act is a great guideline. Think of a 12 year old who cannot reasonably access easily what others do freely without undue financial burden. I should not have to pay for any conversion of van, just the MSR of the original vehicle prior to conversion
- I get the feeling that CCS 'likes' and recommends certain vendors over others. When we were first getting equipment, I felt we had to go with a specific vendor. When talking to other parents (at parent meetings) I found out we could use another vendor as long as they had Medi-Cal clearance. They should have been upfront about this instead of our being told 'this is the vendor we use'. DME should be determined by the therapist and Doctor, not by supervisors or others who say that some equipment is too expensive or we use this for that type of problem. Each client is unique and their needs are unique. The restrictions are not in the client's best interest, but rather financial based or maybe preferred vendor based? Thank you for advocating for my child and for us, her family and caretakers for life.
- Treat the process like a business with deliverables and expectations. Have IDEO maybe come and help you finally do things right and fast. You know, people are nice and seem to try, but the outcome is a disaster!
- Thinks that are everyday things to DME like stairs walking etc. our kids need devices for and parents cannot always break their backs when there is equipment for it.

- The whole process in general is concerning. All families are told up front when requesting to go in to a DME process that it can take at least up to a year. Really? No parent should have to endure that in trying to provide care for their child.
- The MTU units should genuinely be concerned about helping the child and less concerned about reading notes. Equipment and child's physical needs to live their unique life should be the priority. They should also be concerned about all families and making sure the family feels supported! Their needs to be surveys they are monitored by operations or management to insure quality control and best practice.
- It shouldn't be such a struggle to get DME. Families with a disabled child put up with enough, and then to have to constantly fight for necessary equipment is exhausting.
- It's a complicated issue. It just shouldn't take so long - the child grows out of the equipment before they get it. Every issue is different - another case would be for incontinence issues - diapers can be a nightmare because often parents aren't informed that they do not have an authorization in place until the diapers don't show up. Catheters and material for colostomies - giving folks more would minimize the number of infections. I could go on for days about this issue.
- The program and equipment availability and special fitting of the Aprica wheelchairs through Valley Mountain were an absolute God Send! I couldn't wait to pick it up - we were able to go out in public again. It was very nice to have - a luxury if you will.
- CCS, DHCS, Medical, private insurance all need to talk and come up with a better plan for DME products. It is the norm for a wheelchair to take at least 6-9 months. I do not know what the solution is at this point.
- Having a child with disability is very difficult just in self having to deal with the struggle of DME requirements, lack education in the staff world is even more stressful. I urge that parents be actively interviewed by CCS clinics, MTU staff, and DME staff.
- 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.
- Many families have given up because of the lengthy and sometimes complicated process when their children have a legitimate need for DME. I don't blame them. Not all families are resourceful and persistent like myself. It's the children who are not getting their needs met.
- Have the person on charge of CCS at the county level report to someone local instead of a suit in Sacramento
- I've been disappointed with our CCS services for the last several yrs. our therapists are ineffective and they are not willing to budge on any policies that are in place. Requests may require a more personal look into the family/child's needs.
- Make sure that the people determining eligibility have some experience in providing DME. I have had physicians, and therapists, determine medical necessity win, they have never spent a day in a home care situation and/or caring for a child with physical disability.
- Vendors rarely available and opt to make it on their terms. Most equipment that is deemed to be rental is old and worn down. For families who utilize CCS their child's condition is either permanent or long term. Rentals are not in the best interest. Giving the choice back to the physician and family makes more sense vs third/fourth party who don't even understand the actual need

- Maybe they can help getting her afos approved.
- CCS staff have been a great help.

Responses Sent Via Email, Not Part of Survey

- Things get even more complicated when you are coordinating with private insurance. For example, my insurance pays for wheelchairs and braces. But, because the orders come up from the MTU, it goes through a quasi CCS approval process even though CCS is not ultimately going to pay for it. This slows things down both for us and I imagine for CCS only families because the process is bogged down by so many people in the system. Also, the vendors are used to working with CCS and not private insurance so they don't always have solid systems in place. For example, my insurance does not offer pre-approval letters on DME. The policy clearly states what is covered and what isn't and they won't comment beyond that. But, the vendor is used to a model of obtaining a formal pre-approval so I always have to sign all this additional paperwork. The paper work is not the end of the world, but each time it's as if the vendor has completely forgotten the last time so they still try over and over to get the pre-approval letter before sending me the release paperwork. This wastes even more time.

This is related to item 1-there are not enough vendors. It feels like a monopoly. I've never been given a choice for a vendor for anything. I think this "guaranteed business" leads vendors to be a little lax in their customer service (or it's the issue mentioned above that they simply don't have the capacity to manage it all, but you'd think with the guaranteed business they could hire more people). You have to call over and over and if something goes wrong, they don't tell you. They wait for you to call wondering where the item is. Not all families have the free time to be calling over and over.

As for solutions, I think CCS need to vendorize more DME companies and have standards for getting things done. There needs to be competition and clear expectations for what is acceptable customer service. I have a feeling if I had a choice of vendors to go to, one of them would find a way to remember what the process is for working with my insurance company on items that are not going to be covered by CCS so it could go as smoothly as those items that are covered by CCS. I also think we should hold vendors to standards like 8 weeks for a wheelchair. There is truly no reason a basic wheelchair should take 4 months + to order because the holdup is always paperwork sitting on someone's desk, not technical specifications.

- We have had issues with our son not getting a walker with our CCS group in Livermore Valley Unit. I'm always sharing and showing how our son is walking and wanting to walk so much. He is not just a child in a wheelchair. He takes beautiful steps with his right leg and left leg when holding him up under his arms. In a walker he advances forward with only his right leg, but lags with his left. However we are always told that in order for him to get a DME walker, he must show that he can walk continuous steps with his feet, left right left right and certain number of steps and certain distance "in a walker". This is ridiculous. He needs a walker to help him "learn" to walk initially. With these rules they are preventing kids who could walk from walking.

I want to share a video of my son today where he is walking now with the Rifton walker whom we have borrowed from another family because I am always denied a walker for our son due to these conditions. In this video, with the walker after using for almost 1 year now, he is walking independently with the walker. He achieved this with the help of our Conductor (Conductive Education). Prior to this, he was stepping with this walker only on right leg, and an adult would have to completely assist him with moving left leg forward.

By putting harsh rules, I believe CCS is preventing kids the opportunity to walk, and delaying them even further from reaching their goals. My son has had 2 hip surgeries in the past and has achieved this today. There may be several parents out there who are accepting to CCS rules, and not doing

anything on their own to get a walker, borrow a walker, etc., and in turn continuing to having their child in a wheelchair which is sad.

Please look into the rules and guidelines for walkers within CCS, in detail. Would much rather CCS/or government fund us a certain amount per year for DME, so those of us parents who would like to do the research out there can do so and make the decision to buy suitable DME for our child, at the appropriate times. I have run into similar such issues as walker in the past (ie. Hand splints/braces) with them and am bit exhausted where now I try to find my own ways (borrowing/personal funding, etc.) to get the equipment my child needs.