

Overall Summary from CCS Needs Assessment Focus Groups

[Hospitals/Plans, Spanish-Speaking Parents, Transition-Age Youth]

Topics:

- Barriers to provider participation in CCS
- Strategies to overcome barriers to provider participation
- Medical Home for CCS Kids
- Other Comments
- Health Plans be required to provide same coverage –
- More Efficient Authorizations
- Ways of improving the process of determining eligibility
- Reducing County Variability
- Enhancing communication between state and county CCS programs
- Improving Case Management
- Issues coordinating care
- Strategies for coordinating care
- Issues with carve in and carve out
- Care coordination in a carve out situation
- Creation of a specialty plan for CSHCN
- Improving Access to DME
- Services unique to MTP
- How to reduce costs for MTP
- Medical Eligibility Changes
- County Role in Maintaining Standards
- Outcome information to collect
- Challenges and solutions for transitioning adolescents
- Data Collection for MTP
- MTP Best Practice Models
- Solutions to MTP Vendor Issues
- How well CCS is meeting child's needs
- Child's access to specialty providers when needed
- Child's access to primary care providers when needed
- Child's Access to equipment, supplies, and medication

- Areas parents want to have input into
- Communication between Family and CCS
- As it relates to Child, communication among CCS Staff
- Other Issues raised by parents
- Experience transitioning to an adult medical provider
- Concerns about transitioning
- Type of insurance
- What else would be or has been helpful for transitioning to adulthood
- Advocating for self and control of medical records
- Discussion of other issues related to becoming adult

Barriers to provider participation in CCS

- Payment issues, Low rates, delayed payment due to state budget shortfalls(IOWs), and county budget shortfalls
- High standards and low \$ Platinum service for low fees
- Inadequately funded mandates – special care centers don't get adequate reimbursement for requirement CCS patients medically complex and time consuming; huge case loads
- Can't balance bill, even for kids who also have private insurance if they have Medi-Cal too
- Medical decisions negatively influenced by reimbursement rates (e.g. titanium/metal, doesn't pay for certain lab tests and materials
- Issues with genetic testing and billing
- Problem with carved-in plans not paying
- Caring for CCS patients very time intensive

- re payment applying for Medi-Cal #s other admin hassles (EDRS, regs re moving) Billing and paper work too complex

State general CCS Administrative issues

- Lack of power of CCS program to make needed changes to other agencies' policies Elevate CMS to division level to have more power and clout to deal with rates, etc
- Elevate status of CCS Director and increase pay
- Need more state staff with authority with and leadership
- CCS doesn't recognize NPs
- Abandoned the medical home initiative
- Confusion about 'paneling' Even if CCS paneled, can't get past office manager because of low reimbursement

Lack of Provider support

- State does not help providers once enrolled – if they have trouble no one explains the problem
- Lack of training to take care of CCS kids in residency programs
- CCS patients are often medically very complex
- Need for training in cultural competency

Strategies to overcome barriers to provider participation

- State CCS changes
- Simplify paper work.
- Staff for site visits to applicants
- require specialty care centers to recruit PCPs
- have standards developed and enforced by people who really know what is going

- on and are in the field – reality test to make sure feasible
- Change eligibility for CSHCNs
 - When not enough money, re-prioritize. Too much being spent on those with a small chance of survival instead of spending less on more kids and keeping them healthy. Need to restrict care in the extremes
 - When not enough money – need to look at residency requirements. Concerns about people coming from out of state and out to county to get CCS
 - Stop covering acute conditions and concentrate on conditions that last more than one year

MediCal billing changes

- Improve reimbursement rates
- more billing experts within CCS who could create a better billing mechanism
- Separate billing unit for CCS
- Better IT system set up for CCS claims – electronic billing
- develop mechanisms to educate PCPs, materials for all counties

Physician relations/training

- physicians – medical home, transition issue, opportunity for training, tele-med opportunities for consultants
- add CCS training to peds, Family medicine residency programs
- loan forgiveness for PCPs
- tertiary care centers train residents on systems
- For MDs already in practice – individual marketing campaign especially to families is need
- AT UCSF, residents do a CCS rotation
- Tertiary and regional care centers could require a course on government and

- medicine, utilize relationship between regional center and medical schools
- Clear, easy publication that explains CCS
- contacts, should include admin and billing education
- In rural areas, reach PCPs through web or teleconferences
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- Recruiting providers
 - Suggest provisional paneling of residents until they become board certified

Medical Home for CCS Kids

- at special care center, but have PCP and case managers there to manage and needs funding
- Determine which special care center is most important in child's life and locate medical home there
- if PCP in the community, more training and funding needed
- Elements being provided for free by some special care centers and programs, but not sustainable
- Many PCPs not CCS paneled

Service content or design

- State updating of guidelines and re-evaluating criteria for treatments OR, develop relationship with a few center that can be trusted and let them determine
- No dental services
- Abuse of incontinence supplies
- Too many NICUs – financial incentive to keep babies, struggles over transfer
- Families need hospice, psychological and spiritual care.

Health Plans Issue

Concerns of Plans

- concerns that CCS system not sustainable – why make private insurance do the same
- Health Plans agree that CCS has raised the bar for everyone[Hospital/Health Plan comment] I'd love to see that. Issue is who would pay for it

Concerns about plans

- HMOs and PPOs deny services inappropriately
- Families with multiple coverage have perverse incentive to drop private coverage and just have CCS
- Private insurance only reimburses for certain things and uses CCS rates
- Concerns about cost shifting to consumers
- Health plans should pay for HRIF services, newborn screening and hearing loss. HMO should be covering all diagnostics, not CCS
- Insurance should cover MTU
- CCS standards have improved care at non-CCS providers
- Children's Hospital's can reject individual insurance providers to give them feedback – then they have no where to send patients
- For commercial plans, it is employer sponsored – so the employer picks the benefit plan
- Some plans do not have a big pediatric subspecialty provider network.
- Recently encountered plans not covering craniofacial. But you don't want bills remediating specific conditions.
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Suggestions to improve plans

- Need to start with a pilot program of an efficient system.

- HMOs are mandated to provide certain basic benefits – more an issue with dieticians (?CHECK ON THIS)
- Could have discussion about MTP. We think there is significant cost shifting from private to public, because no financial eligibility. Could make a case for plans to be billed, to require reimbursement for OT/PT.

More Efficient Authorizations

- Authorize for longer periods of time (whole year) for those needing frequent hospitalization
- Right Fax – digital FAX to speed up turn around time
- Development of IT infrastructure (some have used bioterrorism \$\$\$)
- Electronic request for services from providers instead of fax
- E-47 – authorizing online (can all access or just large providers?)
- Carved in county worked with Partnership Health Plan on language to reduce paperwork using special instructions – extending into other counties and reducing variability

Ways of improving the process of determining eligibility

- require managed care plans to include medical reports with referral forms
- revise eligible conditions to exclude conditions not chronic conditions (i.e. gallbladder), see medical consultants report
- More county staff to process applications
- electronic links between CCS and hospitals – link institutions
- Adequate state staff for policy development
- Electronic medical records

- Improve process for getting Medi-Cal cleared with the system (can't clear old data on private coverage)
- tap federal funding for electronic medical records
- List of medically eligible conditions for providers
- Provider rural counties help with technical issues
- Could do at special care centers (is this a conflict of interest?)
- Have one application to determine eligibility for CCS, Medi-Cal and Healthy Families (is there not one now?)
- Need to improve conditions that aren't chronic or too complex
- Need state to access federal funding for IT
- Give referral people a list of ICD-9 codes that are automatically eligible
- In rural areas, need to be done locally not by special care centers
- All of the hospitals and the big provider groups have access to PIP/PD and they grant CCS access to their records online which cuts down on paper back and forth.
- Several ways to approach. Centralize it as the state, done by one person. Could look at hospital liaison teams. Look at regionalizing eligibility. Idea of getting CCS medical eligibility consultants together. Need to have technical advisory committee at the state.
- If there was a way to look at eligibility for conditions that require short hospitalizations/treatment – we have a tremendous difficulty with timeliness. They come in and out before CCS accepts them. Need a consistent policy on subset of short conditions.
- Recommend we need to have the same standard for all CCS kids. Rules for

Appendix 11 Focus Groups Data Summary

Healthy Families or Medi-Cal are different. Issue of requesting a retroactive authorization.

- There needs to be more outcome data. More numbers we can compare to bring to the table the reality. Need a transparent system.
- Seems to be diagnosis driven. Some are very clear. But getting into some of endocrine, pulmonary – now we are fuzzy water.
- Very difficult and time intensive to match authorization/SAR to services provided, an administrative issue.

Reducing County Variability

- Need more groups like CRISS MEWG
- More state staff to consult with counties
- Centralize eligibility determinations
- Hospital liaison teams in special care centers to determine financial, medical and residential eligibility cover several counties
- Need data about the problem
- Need statewide meetings
- Regionalize and share same MD making determinations
- More state staff to process dependent county eligibility and authorizations
- For consistency, need 1 person at the state level making decisions
- Many County CCS administrators don't support statewide authorizations
- There's a difference in care covered in CCS. Some are acute based model – point of care is approved, for example getting labs and tests approved. We [Hospital] see variability working with different health plans.
- Some medical directors do not want statewide consistency, they want to have flexibility for their county.

- Local share cost is another issue.

Enhancing communication between state and county CCS programs

- re-establish annual meetings
- webinars about new policies and procedures
- CRISS funded for dependent county meeting, could do other groups
- statewide trainings – need state staff to do this
- updated letters – get county input before issuing new letters
- Need the right staff, with knowledge and authority to attend meetings
- Input from counties before changes are made, for example to numbered letters; could send out to working groups to reduce comments
- State has to willing to admit fault and take suggestions

Improving Case Management

- serving the whole child: mental health, primary care, specialty care
- Social worker on case management team
- Groups like CRISS
- Humboldt tool – diagnosis, numbered letter, and *This Computes* alerts
- Having access to hospital's online records
- Electronic medical records
- Updating numbered letters
- Trouble getting data from tertiary centers
- Case management triage tool – who gets CM – focus on cases that would benefit
- Retroactive case management
- State support for disseminating innovative county tools and templates

- One tool with links to all the regulations
- Diagnosis-based case management teams
- There is a lot of care coordination that happens at the plan level at Health Net. At CCS, it is not possible to do case management for the number of kids per case manager. So a lot of care coordination is happening at the plans, because it is the only way they can access the services.
- Commercial health plans have a lot of programs
- When we [hospital/health plan] work with the CCS, we do care coordination, we sort out the services. But we cannot co-case manage because we could go against CCS case management. But for anyone not on CCS, we do have programs in place.
- Alameda Alliance, had a special needs care coordinator, who did liaison work with CCS and with ones not CCS eligible.
- We place one of the staff at a regional center. Also at a hospital in the central valley. We are piloting different models.

Issues Coordinating Care from the perspective of hospitals and health plans

- Difficult coordinating care, especially when the child has more than one condition
- A lot of issues with the patient being carved out, with a condition, with the conditions being carved out from each other.
- Providers struggle with the authorization process and who authorizes.
- For the authorization process, we have a high level of resources just to navigate the system of the Medi-Cal health plan,

Appendix 11 Focus Groups Data Summary

CCS, and MTU vs Regional Center and what the patient is eligible for.

- Depends on the facility or the providers that is providing the CCS services. In some areas it is easier to communicate with the provider or facility than others. Where we have a good relationship, and can coordinate services well.
- Great difficulty depending on where they are seen, for example specialty care within our system, we have electronic records. If not, the primary care physician is at the mercy of getting the records.
- The queue for visits at the specialty care centers is so long
- Issue around authorizations and getting child seen in a timely manner. We are obligated to refer out for certain CCS conditions, even when we have capacity. We have difficulty locating a center that can care for child in a timely manner.
- Would like to get our units CCS certified, but there's a lag time because of staff cuts at the state
- Biggest challenge is the authorization process between the facility and the CCS office that is managing the case, because we are covering a large area. We have a CCS worker on site, which works beautifully. But when working with other CCS offices, not as streamlined.
- Greater challenge when child moves out of special care services into MD only – have to look at how we are going to coordinate the care. For example, when diabetic is under control, they don't qualify anymore, but under control because in program
- Challenge we have is providers who see Health Families and commercial members – but not Medi-Cal. Need to

get something in place so they can get paid. Providers say I don't even bill CCS because I can't get paid, and I just do it for free.

- The county variation creates significant issues. Can delay initial treatment. For ongoing treatment, it provides families great confusion.
- In terms of the carve out, what we're seeing creating significant difficulties is the transition population who believe they have Medi-Cal, but it is a CCS eligible condition and it delays treatment and procedures.

Strategies for Coordinating Care from the perspective of hospitals and health plans

- CCS to be not as bureaucratic, and consider the whole child as a child.
- Variation depending on the county and on the plan. Some counties have better relationships than others. The plans with the CSS liaison work pretty well. Some simple strategies – electronic medical records. Also, hospital liaison team – based at high volume facilities, for centralization of eligibility and authorizations.
- Great variability across the state - to streamline, we need to get physicians paneled faster.
- Streamline payment, or have a hotline if they have claims that are not being paid.
- Look at the issue to see if it needs legislation or is administrative, about having a concurrent process of CCS and Medi-Cal paneling.
- System of variability for counties, in authorization. Why can't Sacramento office step in and give guidelines for interpreting.

- State agencies that deal with special needs, do not talk to each other. Medi-Cal, CCS, Healthy Families – they all have their own things going on.
- Have to look at the whole system of how CCS looks at what constitutes CCS eligible conditions and what are requirements of a special care center. Some regulations were written 50 years ago

Issues with carve in versus carve out

- It makes for sense for kids with complex conditions, to serve the whole child.
- Putting the whole child together makes sense. And to look at the whole child from a preventive lens. Care in outpatient and special care centers is preventive.
- Other gain – having the PCP at the table helps us look at roles for each provider in the child's care.
- Still look to the health plans to do the case finding.
- There are some gains that can be made, could be some efficiencies. Better to integrate all needs at a special care center.
- Don't think it would improve care. Before medical managed care, they were fee for service. Their care was not better. Also CCS does not provide preventative services.
- May require the rethinking of our conditions, looking at medicine in this century
- Gain might be greater on the administrative side than on the clinical/delivery side. I think they are getting all the comprehensive care they need. It is more dealing with the bureaucracy of the system.

Appendix 11 Focus Groups Data Summary

- Would be easier for the patients and families managed as whole. Families have administrative burdens too.
- There is a burden already on the specialty provider to provide some of these services because they don't have confidence in some of the PCPs. The special care provider spends their time managing primary care.
- There are a couple types of kids. What about a two-tiered system, carving out the complicated complex long term conditions. (exactly what we have looked at in the CHIPRA pilot – chronic vs acute CCS)

Care coordination in a carve out system

- As the health plan, we're responsible for finding the appropriate specialist to handle the needs of the child. Would work closely with the primary care provider to identify the need and then coordinate the access in a certain time frame.
- In the commercial world, it works as described. Primary care provider is the driver, determines the type of referral needed. If we do not have that specialty provider in the network, will refer out.
- Speaking to discharge from the hospital and care coordination – we don't see much difference between whether condition is carved out or child is managed by the plan. Significant difficulties finding providers in rural counties
- Some Counties contract with [hospital/health plan] to coordinate care. For us, this a good way to go because within our own plan.
- Pediatric endocrinologists, oncologists – don't grow on every bush. These are busy practitioners with many cases.

- Trying to find an outside provider, especially in rural, is difficult.
- Some issues with when you give a plan the financial risk, but the authorization are handled by a separate entity – plan has to figure it out. Plan is capitated for the care, but CCS is still responsible for determining correct medical treatment plan. Have experienced where the plan where overrule authorizations decisions – often after the care has been provided
- Financial risk carved in, but medical care decisions carved out.
- These kids are very unpredictable and expensive – not good for a small risk pool

Creating a specialty plan for CSHCN

- There's some benefits to that. Because you can integrate medical management from screening to specialized services.
- From a provider and family hassle perspective – then you have one system taking care of all needs. There is some simplicity created.
- Conceptually, this is an idea we are supportive of, but needs to be properly funded
- [Hospitals/Health Plans] are more the administrative coordinator, we don't make the medical decisions. The other side, the specialty medical care is paid by CCS no questions. Anything primary/preventative is paid by other payer service. Focus is not on condition, but who is providing service.
- Currently the system is about denial, or utilization review. But in a true service delivery model (such as Kaiser), there is discretion, and you can use the resources you have, for example can take benefits and use them in different ways.

- These families don't know they have 2 kinds of coverage. ---like the comment about confusion about who they have. We need to educate the families about CCS upfront when they sign up.

Improving Access to DME

- Improve reimbursement rates – comparable with Medicare
- Set rates based on actual costs (lag between improvements in technology and rates); rates need change as cost change
- Improve rates for especially for smaller ticket items which are reimbursed at lower than the vendor's costs (against federal law).
- Improve DME service codes – need separate pediatric codes
- Improve service date/delivery date issue; might be covered when ordered but not when delivered
- Build relationships with vendors, and local vendors
- Implement a lend or recycle program
- Improve EDS, have billing support, establish CCS intermediary or fiscal liaison with EDS
- Change the law that Medi-Cal is 80% of Medicare
- Needing a system that has flexibility – if need a vendor to stay in the program then want to be able pay to a little more to keep
- Better planning to Identify equipment needs earlier when hospitalized to facilitate discharge
- Allow vendors electronic access to authorizations, but limited number of slots – expand the number of slots
- Need to able to delete an item on a SAR instead of cancelling and reenter (pages of codes for peds)

- More state staff to process dependent counties
- Use Explanation of Benefits (EOB) in lieu of denials because insurers typically provide EOBs and not denials
- Allow alternative payment methods to purchase medically necessary equipment through non-MediCal providers
- Resolve the liability issues that prevent the reassignment of used equipment
- Can have an authorization, but no payment is the issue
- [Hospitals/Health Plans] get the authorization no problem. But we pay because we need the beds
- CCS authorizes equipment at discharge, but if health plan changes at the end of the month, the family is at risk of having it removed from the home. The family doesn't know how to make sure authorization continues.
- [Health plans] have contracts with vendors – they sign with an understanding they will provide it no matter what line is used.
- The DME benefit under the health plans we [hospital] work with, is very limited, only covers a few things. If we go to ask for more, it is asking them to take on a lot of risk. It is really cost shifting

Services unique to MTP

- Provides expertise
- Providers ongoing assessment and monitoring
- Helps improve function
- Reduces future/long term costs
- Helps family manage child's care
- Helps child live a better life
- Is a local provider, familiar with local resources, and able to provide better care coordination

- Works across the state, offering seamless transition for children that move
- Has therapists who stay with the program, which offers continuity of care
- Often serves as the Medical Home for the child
- An integrated medical, educational, and community services model
- Each county MTP has a designated liaison to Education for whole child management
- Provides home and school visits for assessment in natural environment
- Family-focused and family centered
- Offers transition services for young adults

How to reduce costs for MTP

- Look for areas that could be more cost efficient and effective
- Look for evidence-based practice
- Example: short bursts of therapy, coach parent to be expert
- Need more support for clerical and social work issues
- Use clerical staff instead of therapist using time to do those activities
- More technology – electronic medical records, scheduling, access to authorization system
- Look at data and figure out case load assessment – who to monitor, what % direct services and then schedule that way
- Change guidelines on treatment in satellite setting for example, when there is a concentration of MTP kids at a particular school site.
- MTC billing of all private insurance for physician’s time including HMO and PPO kids

- Designate as a Special Care Center, then able to bill for social worker and nutritionist services and other professional categories
- To address low rates/lack of providers: Create a pool of therapists in the regions like traveling therapists
- To address low rates/lack of providers: Utilize SELPA therapists for a small volume need. Integrate the MTP therapy services and the SELPA/school therapy programs

Medical Eligibility Changes

- Cut off after 18, because MTP is a pediatric program and pediatric services are out of sync
- For CCS in general, eliminate some simple, non-chronic diagnoses, (such as fractures), which would eliminate work
- Experience: a lot of time working with CCS general program is spent determining if something is related to a CCS eligible condition
- State CMS should engage in statewide discussion on eligibility
- Maintain existing utilization review to determine which children and youth are still benefiting from therapy or which have achieved their goal

County Role in Maintaining Standards

- Have heard some issues with standards, that they have no legal power; but no one agreed
- Suggestion to get a legal opinion on standards
- We can identify a problem or issue, but a challenge to address or fix it, would need assurances reports would be follow up on
- We can point out the standards they have agreed to follow

- If county staff were involved in site visits, would want approval letters to come from state
- would need more money and more staff – site visits, write reports, travel \$
- should stay at state level
- Could undermine county role of recruitment and relationship building with providers
- County could ID problems and refer to state to deny payment
- Could be joint, county needs to collaborate with state in site visits and reviews

Outcome information to collect

- Extra time spent per child, for example on call for free to keep child out of the ER;
- Not simply measuring ER visits or hospitalization or mortality; these do not define quality; need to look at how many kids were kept out of the ER
- Compare outcomes between centers
- Look at how much suffering we are causing (with extreme care)
- Outcomes to measure need to be different for different kids, using kids are their own controls, looking at different acuity levels, and quality of life indicators
- Look at data on palliative care services

Challenges and solutions for transitioning adolescents

- Free clinic if you live in that area, but from a primary care doctor
- Create job programs so kids will have jobs and insurance
- But do not want them all to have to get full time jobs, want them to go to school
- Let some stay in until 21

- Make it cost efficient to keep them in the system
- Put mandates on the adult side
- Easier to get money for children
- Patients are complicated; even if there is a provider, there is no case management
- Need to teach PCPs to manage care; need to be able to consult specialists
- Medicare when they turn 21?
- Having co-payment for outpatient – would increase respect

- Quality of life assessment
- Would like to make state data comparable to national and international data
- Need same statewide system to enable comparison
- Use of standardized tools, such as classification scales (GMFCS, MACS, CFCS, FMM) to determine client status
- Use standardized tests and Goal Attainment Scales to measure change
- Use Computer Aided Questionnaires to determine family and client issues, concerns, satisfaction
- Collecting tools and deciding on best standardized tools could be activity of Technical Advisory Committee
- State should support upgrades and improvements to MTU Online and MTU Online enhancements should interface with CMS-Net

- Established procedure that if MTP cannot provide a service, at least maintain an annual evaluation, and families call if something comes up
- Establish a Technical Assistance Committee (TAC) comprised of county program therapists to advise the State regarding evidence-based practice in therapeutic regimens.
- Grant smaller counties flexibility and provide guidelines to regionalize therapy services

Data Collection for MTP

- Online electronic monitoring (MTPOnline)
- How long is wait list, how many kids aren't getting what it prescribed
- Can use data to show a therapist how they are doing
- Can use data to show a family how the child is doing; if family is doing something at home, can feel validated, part of coaching model
- Existing scales: American Academy of CP; GMFS classification, Canadian Occupation Performance Measure
- NISS and FISC a good start, but some therapists do not like the NISS and FISC, some think they do not address the whole picture
- Difficult to find one tool to fit all ages and diagnoses
- Need reliability and validity data; (San Diego County did a reliability study and Dr. Boyd has that information)
- Measure improvement of impairment and prevent a child from getting worse
- How to collect data without taking time away from therapy – who should collect the data?
- To get buy-in from families, talk to providers about what MTP does

MTP Best Practice Models

- Riverside changed therapy schedule – doing bursts of therapy in a limited time
- Stricter attendance policy to get families who are really dedicated
- Using data to figure out case load assignment – address staffing shortages by looking at % time for monitoring and % for direct services, and priority scale for waiting lists
- Doing a “field assignment”, rotating PT/OT, clerical staff, and management, to address undesirable sites
- Issue on how to update therapists on child and progress without taking away from therapy time
- In areas where not enough therapists, the state allows MTP to turn them over to the school districts, then they have to reimburse the school

Solutions to MTP Vendor Issues

- Extend Medi-Cal payment increase for doctors to PT and OT
- Hospital-based groups can take more clients than smaller, private groups because can wait for payments
- Improve dealing with EDS – reduce paperwork
- Regionalizing and pooling resources in small counties
- Therapist working nine days (80 hours) so 10th day is over time
- Extend hours of MTPs at schools
- Use summer campus to focus on specific skills
- Do therapy in groups focused on goals
- Use per diem staff, often people who used to work with program
- MTU that is not school based, increases accessibility to families based on time it is open

Solutions to prevention duplication of services

- Some counties bring everyone together to see what everyone provides
- Inform medical liaisons quarterly who CCS is still serving
- State should continue to support this liaison position in each county.

- CCS program sends out letters and request to consult forms to all teachers in September
- Revise policy on duplication
- Numbered letter 11-0279 clearly defines the differences between medically necessary and educationally necessary services

How well CCS is meeting child’s needs

- perceptions of MTU vary; some happy with therapy and also getting active therapy at home, some not getting therapy and unhappy
- Some having to fight MTU to get equipment
- Limited therapy staff – much appointment time spent updating therapists because not consistent
- Location of MTU convenient when associated with school
- Also having medical insurance makes things more difficult because have to get denial, easier to have straight CCS
- Some worked hard to get straight CCS
- LA MTU lacks \$\$ to pay of things
- Co-location of wheelchair clinic and pediatric clinic right at school very helpful
- Some see improvement in services compared to a few years ago
- Cutting of transportation services hard for families
- With CCS, can see all providers in one with special care center and team concept – developed plan family happy with; with insurance, many separate appointments
- Confident with CCS providers because they are paneled
- Vendor therapy worked well, MTU not as good

- PT at Special Care Center said request vendor therapy
- It can be confusing because there are a lot of services and they are divided up, for example, CCS doesn’t cover down syndrome but it will cover if he has other health problems
- CCS staff came to us when at the Children’s Hospital. Very satisfied.
- Yes, CCS provides special food, the only ones who cover it. What will happen at 21?
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Child’s access to specialty providers when needed

- CCS easily agrees when doctor recommends access to specialists
- Specialty clinics don’t do same day and don’t do sick care – say need to see pediatrician for that
- MTU gives permission quickly
- Not a problem is admitted to a hospital
- Services cut for children over 18
- Not dental services for children over 18
- not problems with authorizations or getting in when a planned visit
- Could not get same day appointment and got admitted to hospital
- Does everything possible to avoid being admitted to hospital
- Yes. Daughter had multiple doctors and they always helped
- Have to have an eligible condition, get an authorization sent to the specialist, then wait for an appointment. Can be a waiting list to see a specialist because they have many patients. Then can lose authorization while waiting.
- There are categories for appointments: get seen immediately if in the hospital; but to see a hearing specialist or dentist it can take a year or year and half

Child’s access to primary care providers when needed

- Pay out of pocket for primary care to see pediatrician familiar with child
- Would like a CCS pediatrician, because Medi-Cal pediatrician is not familiar with child/conditions
- Will pay out of pocket to see pediatrician because Medi-Cal pediatrician is not familiar with child/conditions
- Will pay out of pocket to avoid hospitalization
- Experience: Have to pay out of pocket for medications to get child discharged
- Experience: Doctor will call lab without bringing child in
- In ER, doctor will admit because not used to seeing these kids
- Use 911, but CCS doesn’t pay for paramedic services
- If child gets sick, things fall apart, can’t access services to head off illness and child ends up in ER
- Have to go through urgent care or ER which exposes child
- Adolescent care clinic at Children’s wonderful – noticed parent stress and help parent access labs, etc.
- Yes, good
- Problem when the child is not born in the US, they don’t qualify for the Medi-Cal, only emergency Medi-Cal. For example, if a child has a condition, such as seizures, it’s not an emergency, and he doesn’t qualify for a pediatrician. They have to get an authorization, for emergency service. If it isn’t authorized then the bill goes to the family.
- Could avoid the ER if there were better access to appointments to a primary care providers.

- Generally with a child with a special medical condition, anything can become an emergency
- If he gets sick, we try to go somewhere locally but there are no appointments. Then I have to go to Children's Oakland. Sometimes for 3 months she can be fine, or it can be every week or two with a cold or diarrhea.

Child's Access to equipment, supplies, and medication

- Good access to equipment and supplies
- Problems with access to medication
- Regular medication that is not urgent is not a problem
- Medication when admitted for non-CCS condition a problem
- Have to pay out of pocket for medication or wait to get reimbursed
- Won't pay rent or a bill to get medication
- Need available emergency service for equipment
- Experience: Cannot transport equipment/need home services to fix equipment
- Experience: Do have home pickup for equipment repair
- Need education for parents that is basic to explain procedures
- Can do TAR and get reimbursed, pharmacy told her but no one else did
- No handbook, don't know what to ask, have to figure it out yourself or go without
- No social worker, no social worker access
- Parents given no social support – had to ask for help
- For durable medical equipment, for example special shoes or a wheelchair, a child will be measured but it can take

- a year for the equipment to come because there is a lot of paperwork. Then it might not fit.
- Yes, everything that is medication is perfect. Therapy – they will give you 3 or 4 months of appointments. But for equipment, sometime the kids have a special chair and when it arrives, it doesn't fit. A lot of delay
- Have to go to Martinez to get it repaired, and it takes 3-4 days. Can be problem if you don't drive.
- CCS will cover transportation to appointments. But another person said all those funds are gone.
- Can get some services at home. It depends on the case.
- People who provided transport also would provide respite care in the home

Areas parents want to have input into

- all areas
- therapy decisions
- discharge planning
- transition planning
- Parents last to know what CCS doing, parents want to know sooner about workshops, fairs, etc
- Parents not given written notice of what is no longer being provided
- Language or educations barriers/fears about losing services
- Suggestion to have parent groups, through MTU or by conditions, especially when first eligible
- Parents talking to other parents best way to learn

Communication between Family and CCS

- If ask, then told, but have to know to ask
- Sense that staff stays quiet because will have to provide more services

Appendix 11 Focus Groups Data Summary

- Staff tells different families different things
- Lack of communication with MTU staff
- Communication mismanaged – have physical things but communication as person and family missing
- Parent liaison cut from program
- Parent liaisons a good thing
- Doesn't always know who to talk to
- A few years ago, the director organized groups in each therapy unit, and she explained what are the services and in any language they could ask questions. They always listen.
- If we need anything, we immediately call Rita or Ray. And you get a quick response. We identify CCS as Rita and Ray. And at Children's hospital, it is Suzie.
- All my questions I have, they will answer and then ask if I have more questions
- Sometimes the doctors talk – it's like they are not talking about a person, but a condition.
- Sometimes they are very harsh. I would cry and they tried to find other ways to talk to me. Would help if doctors were more sensitive.
- Yes. I have someone to call and she speaks Spanish.
- In the therapy units, like in Oakley, they don't have anyone who speaks Spanish. And it helps a lot when we take the children. And then they can tell us what we have to do with our child.
- The way they assign the cases is by the last name of the child. So they only speak English, so if something happens, then we call Rita. The CM who is a nurse – is in charge of the case, but they do not speak Spanish.
- When someone joins CCS, they get a list of phone numbers. If they call and

speaking Spanish, they are referred to Rita or Ray

- It helps when someone in our own language listens to our frustrations.
- Yes, at Children's, there is a team of 6 doctors and a social worker. At the end, a doctor will stay with a translator, and ask if there is anything I need.
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As it relates to Child, communication among CCS Staff

- Very little communication between therapists and case managers
- The doctors do talk to each other well.
- I think it's about luck – we have a good pediatrician in Brentwood, she sends all the information – even before we call. There was another person before who would not do it.

Other Issues raised by parents

- Parents have info and can help each other
- More parent groups needed
- Training needed for parents about rights and responsibilities in CCS
- Need community-based networking for parents
- Need collaborative groups for medical therapy
- Hired an advocate, made a huge change in her life and for son
- Lucky to have CCS in CA
- Not aware of CCS until Medi-Cal didn't cover medication. Need to advertise the program.
- CCS helped my child; I also need help, support, mental health services. Especially after the crisis/acute care
- At Children's, there is one staff person who talks to all the parents and gets

parents together in the hospital for a support group.

- At the hospital, a nurse showed how to give the antibiotic, in English with a Spanish translator
- There used to be a support group outside of the hospital that was for the whole county but it was too far. It would be good to have a group once a month, for example in a therapy unit because there are a lot of them.
- Sometimes there are a lot of medical records, they tell you what they did with your child, but we do not read medical language, but we don't know if it is good or bad. Need a way to translate it in a friendly way.
- It would be helpful if CCS cared for the whole child because Medi-Cal covers pediatrician, and CCS only covers major medical condition.
- Right now, I don't know who is covering what.
- It would be wonderful if the kids who are undocumented could have access to the pediatrician too. So then they wouldn't have to wait until it is an emergency.
- It would help to have support groups for the siblings. Because sometimes the children are stressed.
- [who provides case management] It's a CCS nurse. But realize the interpreter does it. Or it is Ray.
- For me, case management was in the hospital.
- Sometimes it's frustrating, for example, because the child is receiving PT, but he is not showing improvement, they cancel it. And as a parent, if the child has an appointment every week, with no improvement, then every other week. Then once a month. They leave the case open and review it every 6 months.

And they give us homework to do at home. And it very difficult for us to ask the child to do it at home.

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Experiences transitioning to adult medical provider

- Still see pediatrician.
- Most convenient to see the pediatrician.
- Pediatrician has not talked about transitioning to an adult medical provider.
- Have talked about transitioning generally
- Technically still have a pediatrician, but haven't seen any doctors recently
- Transitioned at age 21 to an adult medical provider within Medi-Cal.
- Mother figured it out. Pediatrician suggested an adult medical provider. No problems.
- Pediatrician will help when it is time.
- There is a general doctor in the practice with the pediatrician
- No one had or has a transition team.
- Made transition difficult: Pediatrician did not know a prescription was needed for a wheelchair

Concerns about transitioning

- Concern on the personality level, because my doctor and I have a really good working relationship. All of my therapy has been very much of a team thing.
- Have known pediatrician for a long time. More concerned about having already established a relationship, and going to a new doctor who wouldn't know me.
- Don't think it will be that hard, already fairly connected
- No concerns because parent works in medical field

Type of insurance

- Private
- Several providers now, will get Medi-Cal
- Have Medi-Cal to qualify but use Private
- On Medi-Cal, difficult because they will not pay for a new chair
- -Have had CCS forever but not really used it, refresh me on what it is.

What else would be or has been helpful for transitioning to adulthood

- Mentorship program with adults with disabilities who meet with college students, to say this is what I did, this is my doctor, to have a point a reference.
- The high school was helpful with transition to adult services and providers, and provided resources such as assistive technology
- When my parents realized I got into this University, my counselors at my high school pointed us to DOR, SSI, and then University's own health care, and did it all before in summer
- Have been to the Center for Independent Living (CIL) - helped with initial IHS application. They have a register of accessible apartments, so I will use that.
- I've not used CIL. For personal reasons, hearing how they interact with you when you go.
- Haven't used CIL yet, but maybe for attendants, if I want to travel by myself
- Through University program, people can apply to be attendants, and then you do the hiring and interviewing process yourself.
- Through the University career center, if people are looking for diversity in their workforce, will match your resume.

- A lot of word of mouth, older students saying go here, do this. Same thing for attendants.
- Have gotten the needed services
- Had a hard time getting desks, because they were not designated for disabled students. Emailed head of program and professor and got it sorted out.

Advocating for self and control of medical records

- My mom talked to me about it. I've been doing it myself
- Have a lot of adult friends with disabilities – not so much taught me, but would if I went to them to ask.
- Something I came to learn on my own. When I moved here away from family, living in a new area, had to talk to specialists and tell them what we need, and with our professors.
- I just did it to a certain extent and I started young
- Coming here, definitely, with my folks decided I would need a set of medical records to carry around.
- Have a file folder of medical records
- My mom has records but can get them if needed
- Don't have a copy but sent one to student health center
- Have nothing in own possession

Discussion of other issues related to becoming adult

- Yes, the psychosocial aspect, the adult doctor talked about it. Concerns related to that, I would go see an adult doctor.
- Not really any doctors, but if I needed anything I could go to the [student health center].
- Yes my doctor always told me she was open to talk to me, but I haven't talked

- Appendix 11 Focus Groups Data Summary about specifics and could if I wanted. Doctor has brought it up.
- Everyone has had sex ed in school
 - [Regarding pediatrician] For someone you have known for so long, it is kind of like your parents.
 - I have a pediatrician, and the wallpaper is zoo animals.