

# Care Transitions for Young Adults With Special Health Care Needs

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## ABSTRACT

**Objectives:** Over the past few decades, children who receive diagnoses that previously precluded long-term survival are living into adulthood. However, they now need to transition from pediatric to adult care providers. Multiple reports document gaps in how this transition occurs, especially for youth with special health needs (SHN). A Medicaid managed care plan (MCP) developed a pilot program for highest-risk youth (top 0.5%) with complex health care needs. The purpose was to address the gaps that exist in the transition of these youth from pediatric to adult care.

**Study Design:** The program model included these key points: no delegation, intensive case management by trained nurses/social workers, and support by plan senior leadership.

**Methods:** Steps to build the program addressed identified gaps, both internal and external to the plan. The model applied the GotTransition Six Core Elements, modified for an MCP.

**Results:** The first 2 patient case studies are presented. Their experiences outline challenges as well as successes. Twenty patients are now in the program. We anticipate adding more patients over the next 4 months—an accelerating growth curve, now that the pathway to meeting these young patients' needs in adult care has been established.

**Conclusions:** Patient feedback and provider participation at all levels continue to improve how the program works. Through this program, plan patients and their parents have told us that the transition to adult care was more successful than they expected. Many youths with SHN could be helped if other MCPs instituted a model like this.

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Pediatric specialty care has made notable achievements over the past few decades. Consequently, children who receive diagnoses that previously precluded long-term survival are now living well into adulthood. These laudable scientific gains have had a perhaps unforeseen outcome—children who in the past might spend their entire lives in a pediatric care system are now living long enough to need transition to adult care providers.

Data show that now more than 90% of children with chronic childhood illnesses reach the age of adulthood.<sup>1</sup> However, only up to 20% of such youth get any transition assistance when “aging out” of the pediatric system.<sup>2</sup> What are some of the issues that these youth need addressed? They include as follows:

- Who will pay for care after age 21?
- Where will the young adult be seen and by which primary care and specialty physicians?
- How will the parent and young adult let go of the relationships they have with their pediatric physicians?
- Who will find new adult health care providers for the young adults?
  - Are such providers knowledgeable about diseases of young adults?
  - Are they willing to accept increasing numbers of chronically ill youth who are aging out of the pediatric system?
- How are these issues affected by a payment structure such as a managed care delegated model, in which young adults are assigned to medical groups and independent practice associations (IPAs) for direct care?
  - This is especially pertinent when IPAs, or even the overarching managed care plan, do not have contracts with tertiary/quaternary care providers.

A clinical review of this topic reveals numerous journal articles documenting concerns that transition raises in patients with medically complex or chronic illnesses. These include childhood cancer,<sup>3</sup> cystic fibrosis,<sup>4</sup> developmental disabilities,<sup>5</sup> diabetes,<sup>6</sup> HIV,<sup>7</sup> inflammatory bowel disease,<sup>8</sup> mental<sup>9</sup> and neurologic<sup>10</sup> problems, rheumatologic disorders,<sup>11</sup> sickle cell disease,<sup>12</sup> and tuberous sclerosis.<sup>13</sup> The American Academy of Pediatrics<sup>14</sup> and the Society for Adolescent Health and Medicine<sup>15</sup> provide resources to assist with a successful transition. The Got Transition<sup>16</sup> project, a federally funded national resource center, has developed Six Core Elements that address how to ensure successful transitions.<sup>17</sup> The Got Transition website has become a core resource for many centers looking to develop a transition program. The Agency for Healthcare Research and Quality<sup>18</sup> and CDC,<sup>19</sup> as well as state and county health departments, in conjunction with federal Title V planning,<sup>20</sup> have also focused on this topic (E.M. Gabovitch, DPH, MPA, MA, teleconference, May 25, 2021; A. Long, PhD, DPH, teleconference, May 21, 2021).

However, none of these resources specifically addresses how a Medicaid managed care plan (MCP) should implement transition planning, particularly for youth with special health needs (SHN). Why should an MCP take this on, one

might ask? Isn't the purpose of the plan to pay for health care services? Don't clinicians manage care?

In the past this has been the case, and perhaps it still is in some states. But in California, especially in the Medicaid managed care program, the managing of care is a key to a successful plan, not just financially but in particular for patients with SHN, via provision of case management services to streamline and remove barriers to care. We decided to use the Got Transition model to assist with developing a program for youth with SHN to effectively transition from pediatric to adult systems of care. We recognize that, due to the early nature of our program and lack of extended follow-up of patients at this time, this is one program's "case study-type" report. However, because of the critical nature of this issue as more youth such as the ones we describe "age out" of the pediatric health care system, we have elected to present the data we currently have to bring further awareness of this issue to a national audience.

## OBJECTIVES

The pilot program, Molina My Right Care (MMRC), led by plan clinicians and case managers, was created to address the ever-widening gap we saw in needs vs services in the adult health care setting for youth with SHN. Here is how it began—with a patient.

## MEDI-CAL MANAGED CARE

In California, starting in the early 1980s, the state Department of Health Services (now called Department of Health Care Services [DHCS]) proposed assigning Medi-Cal (California Medicaid) members into managed care. Initially, federal approval was required to create County Organized Health Systems (COHS), where all Medi-Cal members in 1 county were assigned to the 1 public Medi-Cal plan created for that county. After that, the state developed a "2-plan model" in which a county would have a public plan (sponsored by the county) and a commercial plan (chosen by the state). Then, Medi-Cal members assigned to managed care could choose to join either plan. The third major model type was the Geographic Managed Care (GMC) model; no public plan was created by the county, so up to 5 commercial plans were allowed to bid to be the chosen plans for the county. Later, some small rural counties were moved from original fee-for-service Medi-Cal into the Regional Model—2 commercial plans in the county. Two small plans became offshoots of this: the Imperial Model (for Imperial County—2 commercial plans that serve only 1 county) and the San Benito Model (for San Benito County—1 commercial plan and original Medi-Cal fee-for-service as options).

Most public plans are active in only 1 county. A few also became the public plan for neighboring (generally smaller) counties. These are all COHS plans. The 2 largest plans in the state are the public plan for Los Angeles County (LA Care)—a 2-plan model county—and for Orange County—a COHS county.

Many commercial plans are active in more than 1 county. Our plan is currently active in 5 counties: 3 are 2-plan and 2 are GMC counties.

Both public and private plans use a combination of contracting models that vary on many levels. For the purposes of our Molina My Right Care pilot program, the most important one to be aware of is the delegated model. In this model, premium (per-member per-month [PMPM]) money for Medi-Cal members assigned to a health plan flows from the state, and it is then paid out to individual practice associations (IPAs) or medical groups contracted "downstream" with the plan. These IPAs are responsible for member services (again, paid on a PMPM or capitated rate) that are delegated to them. Often, these are outpatient services (shared risk model) but could also include inpatient services (full risk model). In the delegated model, the health plan contracts with the IPA, and the IPA contracts directly with specific providers in the IPA's region, not with the plan.

In areas that do not use the delegated model, the health plan contracts directly with a provider for member services. The plan then pays a fee-for-service or capitated rate depending on whether the individual provider has members assigned to them. Usually, primary care providers have assigned members and receive a capitated rate; specialty providers do not, and they get paid an agreed-upon fee-for-service rate.

In early February 2022, DHCS released its Medi-Cal Request for Proposals for commercial managed care plans to bid for procurement of Medi-Cal contracts for coverage of California counties. The new contracts will become effective in 2024.

More details about Medi-Cal Managed Care plans and managed care in general are available online.

JR was a construction worker, aged 20 years, married with a new baby. He'd had a motorcycle crash that resulted in major arm injury—deep brachial artery laceration and through-and-through cuts of multiple right arm tendons. He received immediate high-level trauma care at an academic center. At discharge he was told he needed further specialized care to return to full function.

In California, California Children's Services (CCS) is a state program that covers children and youth to age 21 years with chronic and complex conditions (funded jointly by state and federal funds). (See [Sidebar 1](#) and [Sidebar 2](#) for background information on Medi-Cal managed care and CCS.) JR's care was initially covered by CCS. Because of the complex care needed, he was assigned a case manager, who worked with him while he was covered under CCS.

JR aged out of CCS when he turned 21. That left him with regular Medi-Cal managed care coverage. His county is delegated under our plan, so he was assigned to an IPA to manage his outpatient care.

The IPA sent him to 2 community orthopedists who each said that JR needed care that only a specialty center (center A) could provide. Because center A was not contracted with the IPA and its noncontract terms were expensive, the IPA referred JR to a different center: center B. The surgeon there also said that JR needed care at center A. So, the IPA approved a consult with center A's surgeon.

The surgeon at center A examined JR. He said any more delay would further complicate the patient's care. He even said he would schedule the patient on a Saturday to accommodate the patient. He submitted a prior authorization request to the IPA, but it was denied. The IPA said that JR needed to be seen by the previously approved network surgeons to ensure that they could not do the surgery, before approving center A.

By this time, JR was not just frustrated but in despair. We held a telephonic interdisciplinary care team (ICT) meeting with him at his request. He was asked to describe his major care concerns. As he did, he began to sob. He said he had not been able to work since the injury—almost 3 months—and he could not support his family. He just wanted his arm fixed. Our team medical director (MD) agreed. Our MD approved the surgery at center A so there would be no further care delay.

## PROGRAM (STUDY) DESIGN

As a result of this and other similar cases, it became clear to our plan's clinical team that, after aging out of CCS, young adults with the most complex medical conditions were falling through the cracks of our health care network. Their

## CALIFORNIA CHILDREN'S SERVICES

California Children's Services (CCS) is a federal-state program funded jointly by Social Security Act Title V funds and California state/local county dollars. It is one of the longest-existing government programs available for children, as it is one of the original titles of the Social Security Act passed in 1935. Between 70% and 80% of children eligible for CCS also have Medi-Cal (California Medicaid) coverage.

CCS covers children who have chronic and/or complex medical conditions. Medical eligibility is outlined in state regulations and then implemented by county CCS medical directors based on a review of case records. For children not eligible for Medi-Cal, family financial eligibility along with medical eligibility are reviewed to determine CCS program qualification.

More details about CCS are available online.

needed specialty care was not being provided adequately via their delegated IPAs.

This highest-need group was estimated to encompass the top 0.5% of our population of youth with complex health care needs. They made up approximately 6% of CCS patients, who needed active ongoing case management on an annual basis after aging out of CCS.

Led by our MD, we developed MMRC—intended to be a model program for patients like JR. In creating MMRC, we looked at the variety of clinical programs that exist to help youth with care transitions. Numerous children's hospitals<sup>21-24</sup> have created formal transition programs for their patients. Others, such as Children's Hospital Los Angeles<sup>25</sup> and Boston Children's Hospital,<sup>26</sup> provide department-by-department transition assistance. Still others, such as University of California San Francisco<sup>27</sup> and Lucile Packard Children's Hospital Stanford,<sup>28</sup> have specific disease-directed programs or guides for adolescents and young adults.

We also referred in detail to the Six Core Elements<sup>16</sup> noted earlier. These 6 elements were developed for clinical programs, so we found that not all 6 applied directly to the development of an MCP transitions program. Therefore, we adapted the elements as needed to MMRC, using a similar structure but focusing on MCP-type activities rather than hospital or clinical practice ones (see [eAppendix](#) [available at [ajmc.com](#)] on transition activities).

In addition, we identified the following key components foundational to an MCP program model:

- Patients needed to be specifically managed by the plan, not delegated to an IPA, so we could authorize necessary care directly at tertiary care centers.

- We needed to provide intensive case management with nurses/social workers who would work with the patient and/or their parent to address any obstacles to care.
- We needed support from plan senior leadership.

All this had to be done in the context of patients losing their Medi-Cal eligibility, patients being reassigned to a different health plan once eligibility was regained, changing leadership at the plan, and moves by tertiary center champions to other institutions out of state—in short, the usual health care ups and downs.

## METHODS

Persistence does pay off, or we wouldn't have much of a story to tell! In 2019, our first 2 eligible patients turned 21 and aged out of CCS. For MMRC, our goals were that patients with complex health conditions would get the care they needed in the right setting without a lot of red tape—we wanted to cut through the usual barriers to care once they no longer had CCS coverage. We wanted to avoid delays in care and optimize their health status as best we could by having their intensive case manager (CM) work closely with the patient. The steps to meet these goals fell into place and, for the most part, aligned with the Six Core Elements.

Got Transition Element 1 is to develop a transition and care policy/guide. For MMRC, because only a small fraction of our total pediatric membership would be eligible, this consisted of developing clinical criteria for the program that outlined condition severity and complexity. We also established a senior leadership oversight team to ensure equitable application of criteria, with periodic meetings to discuss program updates, complications, and successes. We worked with plan staff to prepare patient and parent program brochures so eligible patients could read about MMRC and understand what it encompassed.

Element 2 calls for a flow sheet registry. We found that regularly updated Excel spreadsheets, along with biweekly multidisciplinary team (MDT) meetings, worked for us. In the MDTs, MMRC clinical leadership and CMs discuss each patient case, address any outstanding issues, and plan follow-up. These standing meetings, or email updates once the patients stabilize, are critical to ongoing team case management of the members and are a main difference between the Got Transition process and our program—MMRC does not end once there is a completed transition because the member's clinical needs do not end there. As long as the patient's clinical condition is active and they remain in the MCP, we continue to care for them in MMRC.

Element 3 assesses a patient's readiness to transition to adult care. This is a component for which we found less congruence between our program and Got Transition. Because a major

aspect of what MMRC provides is intensive case management, and because the patients being served are not typical youth moving from community pediatrics to comparable adult settings, a youth's readiness to take over the responsibility for their adult care is not the initial key focus of the transition—instead, that focus is finding the specific care they need. Certainly, for youth capable of self-management, ongoing education is provided, and the CM gives regular pointers on how to self-advocate, organize and manage their daily care, make appointments, and more. But during the period of transition, ensuring that the patient gets the care they need is the goal.

Elements 4 to 6 include the planning, transfer, and completion of care transition. These did apply to our patients and can best be seen in our initial results, as follows.

## INITIAL RESULTS

### Case Study 1

Our first MMRC patient received a diagnosis of complicated mixed connective tissue disease as an adolescent. He had lost all his fingers to dry gangrene. He had kidney disease and pulmonary artery hypertension. Despite this, he was an easygoing, upbeat young man. After he aged out of CCS, he was willing to join MMRC so he could get integrated care. Until then, his primary care physician (PCP) and his specialists had not really communicated, so the former never seemed to know when he was hospitalized or what his medication doses were. We found this communication gap to be a typical problem for youth going from pediatric to adult health care. Consequently, as part of MMRC, we ensure that the PCP for each of our patients is affiliated with the facility where the specialty physicians work, has electronic health record (EHR) access, can message the specialists and make direct referrals, and the like. This helps avoid PCP–specialty physician miscommunication.

This patient demonstrated many challenges in the planning phase (Element 4) of his care. The initial tertiary care center with which we worked did not coordinate care very well, sometimes would not see him even after scheduling his appointments, and had a lot of turnover of our identified specialists. The transfer of care (Element 5) never seemed to be completed (Element 6). Fortunately, we were able to move him to another tertiary center in the region, and his care has been streamlined since then.

Lessons learned: Often, Medicaid MCPs cannot get contracts with tertiary care centers. This means we have to work with single case agreements. The centers are not really accustomed to these, and without ongoing diligence by the plan, patient care can be interrupted in spite of having these types of contracts. Trying to work with a specific group of primary care and specialty providers who become familiar with the

special program, and educating patients about how their care is covered, can help overcome this access barrier—but it takes resolute planning (Element 4) to achieve it.

## Case Study 2

Our second member was born with complex congenital heart disease. She was followed at a local children's hospital for years. She developed sequelae including protein wasting and lymphoma. She was on daily total parenteral nutrition through a central line, received numerous medications by intravenous line and gastrostomy tube, and needed 10 hours per day of private duty nursing to administer these. She also received weekly blood product transfusions. Despite this support, in the year prior to MMRC, she had frequent hospital stays. When she aged out of CCS at 21 years, her care team was concerned about how transitioning to adult care would occur. They were extremely leery of any adult program being able to care adequately for this patient, whom they quite frankly had kept alive for the previous 10 years. However, their hospital licensure did not allow them to follow patients 21 years or older except for emergency circumstances. Thus, a transition plan had to be developed (Element 4).

Given how ill she had been, all options for the future were discussed with the patient multiple times. She quite clearly reiterated she was not ready to choose end-of-life care. The patient was very cognitively intact. When she wasn't in the hospital, she was happy with her life—she read, went for short walks, and played on her computer.

Our challenge was to set up an adult care network near the patient's home who could take over from the children's hospital team. Each piece of her care had to be established before the children's team would agree to transition her to an adult team. Additionally, the patient was very bonded to her children's team. The ICT met with her to discuss transition plans, and she stated she couldn't imagine going to other doctors. This team had taken care of her and seen her weekly for the past 10 years. But they explained they had no choice, so she agreed to try.

These are classic types of issues that patients with chronic childhood illness who transition to adult care must address. They encompass more subtle aspects of readiness (Element 3) that can complicate planning as well as successful transfer of care (Element 5).

We knew that we had to find comparable adult specialists who could care for our patient. Because of her complexity, we couldn't merely refer the patient to these physicians once we found them. Our program MD called each of the physicians to discuss the patient and get their consent to follow her. After this, the PCP was identified. We found that the Internal Medicine–Pediatrics program at the center was an

excellent PCP resource. Because our patient had never been cared for by anyone but a pediatrician, having a physician with pediatrics training seemed ideal; they would understand the developmental issues she faced from being chronically ill all her life. And having the internal medicine training would help as she developed complications more common to the adult population.

Once all the physicians were in place, we held our breath as we arranged first appointments for our patient. It became clear that fear of starting at a new center was a potential obstacle, so the patient's nurse CM arranged to accompany her to the first appointments. This was also important so the CM could ask the questions identified as necessary to ensure that next steps for care were in place. The patient and her guardian (an older relative) were delighted to have the CM attend the first transfusion service, as well as the first PCP and cardiology visits. After that, amazingly, the patient said she felt comfortable enough to go alone to the subsequent specialty appointments. Readiness progress (Element 3)!

This transition took an incredible amount of planning to increase the likelihood of success for this fragile patient. Because our program was an MCP model, we had the ability to provide ongoing monitoring, with intensive case management and flexibility for financial remuneration to the superspecialists needed, leading to a greater likelihood of successful transition completion (Elements 5 and 6). This was hoped for, but until we saw it in person, we were not sure it would work.

And that wasn't the only evidence of progress and success. In the 6 months prior to joining MMRC, the patient was hospitalized so many days at the children's hospital that it cost the plan almost \$1 million. In the 9 months after her transition, with intensive case management, hands-on interaction, and the ability to get care 20 minutes from her home instead of 2 hours away, she had only 1 hospital stay for sepsis, which cost the plan \$13,000. And she reveled in her improved health status, spending more time at home instead of in the hospital.

Lessons learned: Relationships, as well as high-quality primary and specialty care, are key, especially for the most complex patients needing transition to adult care. Intensive case management is time consuming, but putting in the extra time needed to build patient trust is likely the only way a patient will comfortably move from a beloved pediatric team to a new adult team.

## DISCUSSION

After these first 2 patients, MMRC has expanded to include 18 more patients for a total of 20. Five of these are in a special category for youth near end of life. All are youth who aged out of CCS and continue to need a higher level of care

than that available in the adult community health setting. In addition, growth of the program is accelerating. Whereas in the first year of the program we went from 2 to 4 patients, in year 2 we have added 16 patients, 10 in the past 6 months. Our algorithm is based on problem solving on a case-by-case basis once a patient is identified as eligible for MMRC. In some ways this is improvisational, as each patient's needs are unique, often requiring individual plan outreach to new specialists or different programs at tertiary care centers. But we continue to follow the blueprint that Got Transition and our first cases have established.

The model of using an MCP to facilitate the care transition of youth with SHN has unique pluses. Case management is already a known MCP function, so scaling this up to increase the intensity of services provided to these youth can be planned for based on patient numbers. Members usually continue in the plan regardless of aging past 21 years, so the MCP can ensure that ongoing care is provided in the pediatric and adult settings. The clinical leadership in the plan focuses on patient needs in the program. Therefore, as noted above in our case studies, our MD recruited and communicated patient details with new specialists and PCPs for each patient. The MMRC team ensured that any information needed about previous care, medical records requested, single case agreements, and so forth were in place as care began, facilitating many steps that would be challenging for individual PCPs or specialists in practice to carry out. And we specifically monitored visits via patient communication and EHR notes to ensure that appointments happened, saw what follow-up might be needed, and facilitated any next steps. We believe that this additional intense support has helped immensely in maintaining patient stability in the outpatient setting.

### Limitations

As we continue to work on expanding and improving our pilot program, we are looking at how to quantitate any findings we establish. With our initial small N, our results currently are qualitative. Because we do not have a year's worth of follow-up for most of the program members, we are still analyzing any possible outcomes, including overall savings generated. We recognize that our findings may end up being descriptive even after we do have longer follow-up, considering the small sample size.

But as we enter more patients into the program and have experience with them pre- vs post entry, we are collecting data about hospitalization frequency and cost, outpatient visits, and medications, as well as patient satisfaction with the program, so that our program can become even better. We are looking at lessons learned, as noted above, for future improvements.

### CONCLUSIONS

One of the most important accomplishments of our program is that MMRC has become an established entity at our plan. Every senior leadership member is aware of the program. They each understand its importance in facilitating transition to adult care for complex youth aging out of the CCS program and their ongoing care thereafter. This is an important lesson learned—without the support of senior leaders at the plan, we couldn't have had staff assigned to provide the level of intensive clinical support and case management that these complex patients needed.

In addition, we have developed workflows so new CMs know what their roles are. We have strengthened the relationships with our tertiary care centers. We have solidified the processes to set up single case agreements with members' new physicians and facilities. All of these align with the Got Transition Six Core Elements.

We also know from the regular feedback received from our patients that we have made life easier for them. Repeatedly, both patients and parents have expressed how the transition has been much better than they ever expected. Another lesson learned: Parents want and appreciate having a specific touch point (their CM) to whom they can reach out when they have not received a needed prescription or an appointment with a specialist when they requested it. As noted earlier, this is a key resource that MCPs are particularly geared to provide.

MMRC has done something that every health care program should strive to do: addressed the needs of our most vulnerable patients and cut through any red tape, so the patient can get the right care when they need it. If this model were adopted by other MCPs across the country, the care transition of patients such as these would greatly improve. And the extended life expectancy that these youth have gained from pediatric technological improvements can continue as long as possible, with support from intensive case management, which values each patient and provides ongoing patient advocacy—something that never gets old, no matter what age our patients are.

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## **eAppendix. Molina My Right Care™ (MMRC) and the Got Transition Six Core Elements™**

In developing the MMRC program model, we looked at the clinical programs that exist. We also referred in detail to the Six Core Elements™ developed by Got Transition. These six elements were developed for clinical programs, so we found that not all six applied directly to the development of a managed care plan program. Therefore, we tailored the program we created to the concepts as follows:

### **1. Transition and Care Policy/Guide**

- a. This element applies to any program—and did to ours. We developed criteria as well as an algorithm for the process we would follow to:
  - i. Determine which members would qualify for our program
    1. Unlike pediatric clinical programs where all patients have to be transitioned to new adult providers, or where patients are transitioned from pediatric to adult care with the same providers, we had to identify which patients out of our total plan membership had significant special needs that warranted being referred to the new program we were developing.
    2. The new program was targeting those special needs youth who, in addition to aging out of pediatric care, had a level of medical vulnerabilities making it essential that they received assistance from the plan to ensure they transitioned to the appropriate adult

primary and specialty care providers who could properly care for their complex clinical needs.

- a. For MMRC, we defined these patients as youth who had received care from the state California Children's Services (CCS) program, with complex chronic medical conditions, in need of intensive case management and ongoing adult care that could only be provided adequately at the tertiary care center level of care. (See side bar on CCS for more info on this program.)

## **2. Tracking and Monitoring**

- a. This element applied to all the patients joining our program. However, we didn't develop a formal registry, as indicated in the Got Transition (GT) element. Nor did we develop a specific flow sheet for the program, also given as an example on GT's website. Instead, we used Excel spread sheets as our tracking data base tool and log; we held bi-weekly multidisciplinary care team meetings where the patient's assigned intensive case manager reported on any active issues for the patients, which were added to the tracking log, discussed with the team, including the Medical Director and Program Manager, and noted action items with due dates and assigned responsible parties, so that needed services did not fall through the cracks.

## **3. Transition Readiness**

- a. This element was less applicable to a managed care plan program than a clinical one. This was due to a number of reasons:
  - i. We were not handing off our member from our program to another—we were continuing to follow them from their pediatric care to adult care, with the key resource of an intensive case manager assigned to assist as the transition occurred.
  - ii. A number of our youth were intellectually/developmentally disabled, and not going to be able to take on the transition tasks a typical youth might be able to do. We were working with their parents, who had been managing these tasks all along.
  - iii. For youth who were able to learn the transition tasks, the patient’s case manager provided ongoing education to the member about how to advocate within the health system for their needs, take their medications, etc.; however, we understood that external assistance (e.g. case manager, parent) was also likely to be needed during the transition period due to the complexity of the patient’s medical condition.

#### **4. Transition Planning**

- a. For our program, this was the core component of what was included in each patient’s transition preparation. Because of each patient’s unique and complex needs, this was the most demanding step, requiring detailed problem solving. This component is where our most “improvisational” skills were required, because we were starting from scratch with each patient. Basically, we had to

determine which providers we would obtain to follow these youth after they aged out of the CCS program. We looked at what specialty care each youth was receiving prior to turning 21; we then determined what would be comparable in adult care. De facto all the youth in MMRC had to require care at a tertiary care center to be eligible for our program. While the Got Transition guideline suggests that a program would “(a)ssist youth in identifying adult clinician(s)...”, we knew this was the key barrier for our members—who would see them, and accept the member? So this was where most of our energies were expended for each of our patients after the patient and family accepted the MMRC program. While the individual steps for each patient might need to be created de novo due to each one’s unique circumstances, the overall game plan was a structured one—seek specialty care, then get primary care at the identified tertiary care center in the patient’s region.

- i. This may seem like a straightforward issue, but it is not. As noted in the beginning of our article, there is a dearth of adult specialists trained to care for some of the rarer conditions our transitioning youth present with, particularly the neurologic and genetic conditions they are now surviving with. Our Medical Director spent hours calling specific subspecialists to see who would be open to following some of these members at the various tertiary care facilities in a patient’s region. Most wanted to see the patient’s medical records first, and they also had to be sure, if they were in a group setting, that they had someone who could cover for them when out of the office as well. Once that was established, then primary care

affiliated with the same tertiary care center was arranged. Each piece had to be painstakingly put into place, so that the patient's care could begin.

ii. As is the case for most Medicaid managed care plans in California, our plan is not contracted with many of the tertiary care facilities where these transitioning youth need care. So, before they could be seen, special single case agreements needed to be arranged. Prior authorizations had to be approved for all services, since the care is out of network. Each of these pieces had to be taken care of so the patient could receive all the complex services they needed. This applied to both primary and specialty care.

1. Because of the many needs of these patients, our clinical team facilitated communication with the new medical team. Our Medical Director contacted and spoke with the needed adult specialists and primary care physician at the tertiary care center. The pediatric providers were available if needed, but generally the clinical summary our MD provided, along with previous records, were what the new physicians wanted. We found this helped speed up the transition process.

## **5. Transfer of Care**

a. While this step may be a major one in a clinical program because care is often moving from one set of providers to another, in the managed care plan arena, this was less "climactic" because our MMRC team and the patient's CM were

facilitating and monitoring the transfer. We ensured the patient had transportation to the appointments at the new center. We followed up with the patient to see the results of the appointment. We often had access to the center's electronic health records (EHR) so we could see the specialist's assessment and help with next steps. If something fell through, we could react immediately to determine where an obstacle or barrier was, and plan again. Though this was quite labor intensive, our plan leadership and team believed it was worth it for these highly vulnerable youth who otherwise could end up with deteriorating health, and a potentially avoidable hospital stay.

## **6. Transfer Completion**

- a. MMRC doesn't end once the adult care is in place. We know these youth have ongoing needs, and many have conditions that will deteriorate. Our program is geared to address ongoing needs until the patient no longer needs the additional supports MMRC provides. This is a benefit that having a transitions model in a managed care plan offers.
- b. We considered success the ongoing linkage to care, provider continuity in caring for our patients, and patient/parent satisfaction with the care they were receiving. One specialist visit encounter wasn't enough if two others the patient needed didn't happen, or a needed follow-up visit wasn't scheduled. Having the intensive case manager actively monitoring the patient's care, with biweekly MDTs including team clinical leaders to help regularly problem solve issues that might arise, before, during and after the transition, has facilitated the successful

transition of our cadre of patients so far. With more time since transition, and ongoing data analysis to look for ROI and member satisfaction, we hope to demonstrate quantitatively what we have seen qualitatively.