

Cecilia's Story: Helping Marginalized Families Thrive

Mariana Ledezma-Amorosi and David Aylward¹

September 2020

The current pandemic is a searing indictment of the United States' healthcare system, highlighting its flaws and disparities while underlining the courage of millions of providers. Extraordinary inequities are on full display. No one involved in American health should be surprised that those with the least are being hurt the worst, particularly those of color. It does not have to be this way. We could have a system designed to help vulnerable families thrive -- rather than monetizing sickness.

The new system would consist of collaborative, integrated, and family – centered design and delivery of the necessary primary care and social supports for each vulnerable family to thrive. A peer navigator/coach would work with each family as a single point of contact to design and coordinate individualized support programs.

A new formal collaboration between primary care and local social service organizations would organize the system, streamline applying for and delivery of services, and share data on progress and outcomes. Changing the metrics for which society pays providers from today's sickness and social failure to tomorrow's thriving and equity would facilitate increased prevention and upstream investment by combining and braiding existing funding streams with additional funding from investors.

This story describes the experiences of "Cecilia" with the current system, and then presents a different, more equitable vision² of community health which should produce far better outcomes for less overall cost.

A Single Mother who is Pregnant and an Immigrant

Cecilia³ is a pregnant single mother who emigrated from Central America to the US three years ago. She had experienced severe trauma from gang violence in the poor neighborhood where she lived in her home country. Her mother, Susanna, helped her move. She is glad to have legal status. She has a stable job working for city government. She has decent private health insurance with a reasonable co-pays and deductibles that she can afford, covering her and her son. She has a three-bedroom duplex in affordable housing owned by the city. She shares it with her mother and her two-year-old son, Robert. Cecilia is pre-diabetic and overweight, but not obese. She suffers from moderate depression from time to time. She knows that she is far better off than many of her neighbors, but she is very worried about birthing and parenting her second baby.

Robert is a sweet young boy who has recurrent wheezing suspected to be asthma. Cecilia thinks he has ADHD because both her mother and the neighbor who cares for Robert three days a week say he is hyperactive. When he is not jumping around, he spends a great deal of time watching television and

¹ Mariana was the Associate Director of the Community-Campus Partnership of the Anschutz Medical Campus of the University of Colorado. David is an Assistant Clinical Professor at the University of Colorado School of Medicine's Department of Family Medicine and a Senior Advisor to the Farley Health Policy Center.

² This story is an imagined implementation of a transformed health system based on the outline "Transforming Community Health: Seven Pillars of a New System".

³ Cecilia, Robert, Susanna, and Rita are based on composites of people the authors know. The Metro Community Commons is a vision of a different approach to community health.

videos. Cecilia knows that he needs a better environment and more attention if he is going to succeed, but she can't afford anything like the Montessori schools she has read about.

Susanna is 68, a US citizen, and is dually eligible for Medicare and Medicaid. Her only income is Social Security. Her husband died a few years ago. She babysits Robert when the neighbor cannot. Susanna is obese, diabetic, and has high blood pressure. She has moderate depression and engages in "sheet therapy", often staying in bed except when Robert cries. With Susanna's Social Security and Cecilia's paycheck, they just meet expenses. Cecilia knows she needs more education for a better job with a higher income.

Nightmares about the Birth of Her First Child

Cecilia still has nightmares about Robert's birth two years ago, before she had a better job and insurance. Her English was not particularly good at the time. She did not know much about the culture. She did not know the medical system. She had not established a network in the community, and she had never received instruction in parenting skills. Cecilia worked as an assistant manager in a Latino restaurant. The owner was a kind woman who gave Cecilia two weeks of unpaid leave after Robert's birth.

Cecilia was scared and did not know what to do. Her mom was not a lot of help. She was told by a co-worker to go to the nearby hospital when she went into labor. Happily, Robert's birth was uneventful. The next day the hospital sent her home with her new baby and detailed written instructions on how to care for him, including a pamphlet on breast-feeding. The transition was a complete shock to her. She realized she had no idea what she was doing. Later she was told that the bad feelings she was having had a name: postpartum depression. She did not want to get out of bed many mornings. She felt lots of shame about her feelings. In her culture there is a great stigma around depression, so she did not tell anybody. She suffered in silence, knowing that she was not giving Robert needed love and attention.

She tried breast feeding. Her breasts started to swell, and one was inflamed, so she went back to the hospital. After treatment, the hospital sent a nurse to visit her home and teach her about breast-feeding and other related matters. The nurse connected her with an organization that provided regular home visits by nurses. This was a big help, particularly because they spoke excellent Spanish.

They gave her a contact list for support resources available in the community and helped her prioritize making appointments with them. Her visiting nurse described how the health system works, which was a revelation and scary in its complexity. The nurse screened her for depression and stressed the importance of getting connected to behavioral health care. She also provided some counseling about caring and resources for Susanna, although she stressed that her job was Cecilia and Robert.

The appointments list for all three was long: primary care, behavioral health, dentistry, new parenting classes, job training, and cooking classes at the food bank. Over several weeks, she made appointments and took the bus to the various offices, sometimes taking Robert with her when the neighbor couldn't watch him or when her mother wasn't feeling well. This process took quite a while because she had to match her work schedule with the provider organization and get herself by bus to locations spread around the Denver Metro area. Sometimes she missed appointments.

Once at the appointments, she found it frustrating that she had to tell her whole story repeatedly; it was painful to relive over and over the trauma that drove her out of her country, like ripping off a scab, she

thought. She filled out so many forms; all seemed to ask the same questions. She had to duplicate the process often to get care for her mom and Robert. None of the groups had family appointments.

Now she was about to face the whole process again with her second baby. Plus, her mom was gradually getting worse, and therefore needed more care from her while being less helpful in caring for Robert.

Cecilia and Her Family Face Long Odds

Susanna is headed down a very common, unhealthy, late life stage road, one that will reduce her quality of life, decrease her ability to help raise Robert and the new baby, AND be very, very expensive for both Medicaid and Medicare. The government will pay increasingly large bills for the complications of her diabetes and her co-morbidities. Soon her medical bills paid by taxpayers will total tens of thousands of dollars every few months as health crisis is followed by health crisis. Cecilia is afraid that will be her fate as well, and the probabilities of that sad outcome are high.

Robert is not getting the diet, cognitive stimulation, and emotional support that is essential in these early formative years. The risk factors for a failed life are beginning to accumulate for him as well.

It doesn't have to be that way. Let's change Cecilia's experience for her second child with a new approach designed to help her family thrive: the Metro Community Commons.

Changing Cecilia's Experience. She Joins the Metro Community Commons

A friend told Cecilia about the new Metro Community Commons. She made an appointment with a Commons Companion named Rita, who came to visit Cecilia at her home. Cecilia was delighted that the Companion was someone just a little older who had come from a neighboring country a few years before, spoke her language, and also was a young mother. She told her mother later: "Rita understands me. We've been through a lot of the same things." Rita spent a lot of time with Cecilia getting to know her and her story. She gently explored the kinds of issues Cecilia was facing, along with her hopes and dreams. It was clear to Cecilia that Rita was getting a comprehensive picture of her goals, strengths, weaknesses, and challenges. That was comforting. Rita explained that the Metro Community Commons is a collaborative of community social service organizations, partnered with a primary care clinic with a long history of serving anyone who needed care, and government social agencies. The Commons was ready to provide an individualized program supporting her.⁴ Its mission is to deliver an integrated services program to people like Cecilia⁵.

⁴ Several years before, this collaborative was formed by community leaders and social service groups, the clinic, and a university to improve the health and well-being of their vulnerable neighbors. They designed a new model family support system focused on helping people to thrive, rather than waiting until they were sick and then "repairing" them. The medical experts knew the absence of medical care is only responsible for about 10% of premature death. Genetics and social determinants interact to cause 80-90 percent. The community and government organizations that provided the social supports vulnerable families need (housing, food, training, employment, day care) joined in the collaboration with the clinic and university.

⁵ The Commons issued a social impact bond to finance its program of clinical and social services. The proceeds of the bond were distributed to the providers in the Commons according to their work for its members. The investors in the bond were a group of social impact investors that the Commons helped recruit, working closely with them to identify the organizations like Medicare and Medicaid, the corrections system and others that would benefit if and when the Commons program is successful. The Commons issues a new bond every few years to cover services to its expanding membership as more people like Cecilia and her family join.

Rita said that she and Cecilia would develop a plan to use these services and explained how that process would work. The most important part, she said, was understanding Cecilia's priorities for her family overall and then for each person in it. "We focus on the family, not just the individuals in it," she said. She explained that she would be consulting with two kinds of experts and then getting back with Cecilia to develop the plan. Joseph, the expert navigator and plan developer of the Commons would help Rita translate Cecilia's desires and needs into a specific plan over time with measurable quarterly milestones, reminders, checkpoints, and desired outcomes. Rita would also be consulting with her supervisor, a 20-year older version of Rita, with deep experience in the community.

Cecilia's Family Success Plans

Rita was back a week later, and the two women spent a couple of hours poring through options and details on Rita's laptop, working on "Cecilia's Family Success Plan." Cecilia felt like there was a whole organization whose mission was to help her get through life successfully and said so to Rita. "That's exactly how we want you to feel," said Rita. Rita stressed that she and the Commons could only provide support; Cecilia needed to be the leader of her own plan⁶.

Rita said she was the point of contact for the Commons with Cecilia and her family to make sure that the plan was properly implemented and that adjustments were made along the way as needed by the family or by changes in events. She gave her cell phone number to Cecilia and said: "Call or text me anytime." Cecilia signed her written permission on Rita's tablet to share the information that Cecilia had provided, including the plan, with members of the Commons who would be involved in implementing it⁷.

Then Rita and Cecilia repeated the whole process with Susanna. They also developed a plan for Robert, and one for the new baby. Getting this done with Susanna was quite a project as anyone who has cared for an older parent knows, but both Rita and Cecilia relied heavily on the power of "grandchild motivation". "Mom, you need to be strong for Robert and for your new grandchild." That finally won her over to adopt a nutrition, weight loss and exercise program, coupled with joining a seniors' program at the Metro Commons Community Center twice a week.

Rita helped Cecilia download the Commons Member App onto her smart phone. This allows Cecilia to see at any time how she, her mom, Robert and later the new baby are doing on the plan. It provides reminders, tips, and other helpful information. It gives Cecilia 24 x 7 access to the Commons system to ask health or other questions. It allows her to add other neighbors and relatives in a support network for certain of her goals. Twice a week she enters specific vital signs for herself and Susanna; once a week for the Robert, allowing the Commons team to monitor their progress and spot trouble early.

The first part of the plan was getting the whole family signed up at the Metro Commons Community Clinic for their first appointments for primary health care: physical, behavioral, and dental health all in one place, with warm handoffs between the three parts as needed. Cecilia was delighted at her first

⁶ Rita had received a lot of training in coaching and "motivational interviewing" that helped her empower people like Cecilia who previously did not think they could exert control over their lives and their health.

⁷ There were some parts of Cecilia story that she wanted kept private from everyone except Rita and her behavioral health provider. Rita made those notations in the electronic record, and Cecilia gave her electronic approval for sharing the rest.

appointment where the whole family was scheduled in the same period, and they already knew her story. There was childcare for Robert while she and Susanna had their appointments.

Part of the plan was a “Ready for Baby” checklist: monitoring living conditions. How prepared are you for the baby? What classes do you still need? Do you have all the equipment you need (the Commons has a store with a revolving stock of baby equipment and clothing)? Cecilia noted that she needed a new playpen and some extra blankets. They planned the transition from the hospital to home in detail to avoid the trauma of Robert’s birth. That included the schedule of visits by nurses and other Commons members in the period after birth to check on the baby, but also Cecilia, Robert, and Susanna. Rita explained that how Cecilia was feeling about herself and how she was thinking about the new baby were critical. She encouraged Cecilia to discuss those feelings in detail with her Commons team.

Cecilia signed up online to be part of a group of women at the same stage of pregnancy. In addition to being able to communicate with them through the Commons App whenever she wanted, the group had regular group meetings with the Babies Coming Team at the clinic, and with specialists as needed.

The Metro Commons Community Center

Part of Cecilia’s success plan was to visit the Metro Commons Community Center one evening when representatives of all the relevant social services organizations participating in the Commons would be present, creating a one-stop shop. With that available three evenings a week and all-day Saturday, it was easy for Cecilia to find a convenient time.

- WIC: she met a nice caseworker and signed up for nutrition classes, and special vouchers to get more nutritious food.
- SNAP: she signed up for benefits. She worked out a family nutrition plan.
- Fun food and cooking: she signed up for the Commons cooking classes in the Center’s community kitchen and joined the on-site farmers market/food bank, visiting it every week for fresh fruit and vegetables.
- A career counselor developed with her a plan for her employment and professional advancement, starting with some short certificate courses from the local community college offered online and in the community center to teach her some IT skills.
- Cecilia signed up herself and her new baby for a home visiting new baby support program.

Robert’s plan had several sections including:

- arrival of the baby
- getting mold out of the neighbor’s house where he received daycare and the carpet removed from Cecilia and Susanna’s home
- his part of the new family eating plan
- a program around his cognitive development, including regular reading and singing time at home and sensory programs that coincided with Cecilia’s cooking classes
- a special focus on making sure he was getting the affection any child needs.

Susanna’s plan included:

- Twice a week exercise classes at the Center, each time including a social dinner following the class

- Joining a group nutrition and weight loss program
- Once a week talk group for women her age with a psychologist
- A new regimen of medicines to control her high blood pressure
- A smart phone app for Cecilia's phone to register and report her blood sugar levels daily.

On her first appointment at the clinic, Cecilia was delighted to find that the Physician's Assistant and Medical Assistant who are responsible for Robert work closely with specialists at the children's hospital. When they don't know the answer, they can get answers to most questions within a day using something called an eConsult system, meaning Cecilia doesn't have to make a separate appointment and take time off to take Robert to see a specialist. She also learned from the clinic that they have a medical-legal partnership that can assist with landlord issues if they have a hard time getting the changes made to her home and that of her neighbor to prevent Robert's wheezing.

What would you change about the above? What should the other new elements be?

This is a work-in-progress designed to illustrate the difficulties vulnerable residents of communities face in finding and navigating solutions to their social and health needs, and to envision a more equitable and efficient system to support them in leading healthy, successful lives. We encourage comments and criticisms. Please email them to us. david.aylward@cuanschutz.edu; marianaledezmainco@gmail.com.