Spring 2017

From the CEO's Desk: Carmen Ibarra



Last month, Achievable and community health centers across the country got some good news on the federal level. A bill with the potential to dramatically impact health care funding for the people we serve was pulled from the floor of the House of Representatives for lack of votes. Our hope was that any proposed fix to the Affordable Care Act (or Obamacare) would not threaten health care services received by the most vulnerable in our community - those with intellectual and developmental disabilities (I/DD), and the low-income populations we serve. Unfortunately, this good news was short lived and our high hopes were dashed when the House of Representatives passed a new version of the bill known as the ACHA (American Health Care Act). The next step is for the Senate to debate and vote on this bill.

Although a full analysis of the newest version of the ACHA is yet to be done, we can expect significant changes to funding for the Medicaid program (called Medi-Cal in Cali-

fornia). Cuts to the dollars received by the State and the services received by Medi-Cal recipients are very likely. Medi-Cal recipients include individuals with intellectual and developmental disabilities and those living at or near the poverty level. The vast majority (72%) of the patients Achievable sees are on Medi-Cal. Without a doubt many will lose their insurance or they will experience a reduction in the health care services they receive.

As problematic as this bill is, there is yet another threat at the federal level to community health care centers like Achievable and the patients we serve. This looming threat is the so-called "community health center funding cliff." When the Affordable Care Act was passed, it included a funding increase for community health centers for five years. This was part of an effort to increase health care access for low-income children and families. That funding was approved again by Congress two years ago in a bipartisan fashion, however it will expire on September 30th of this year if nothing is done by Congress. While both parties in Congress resoundingly support funding for community health centers, the current contentious environment around health care could threaten 70% of the current funding!

I've said a lot about government programs and used a lot of acronyms so I feel I have to quote President Trump by saying, "who knew healthcare would be so hard." At the end of the day it does not matter what political party we belong to, what matters is to work together to ensure the most vulnerable in our community can continue to receive quality health care at Achievable and the many community health centers out there that do great work day in and day out. At Achievable, we believe access to health care is a right and not a privilege. We hope our representatives at the federal level agree.

Story of Hope: Can Family Finds Footing with New Diagnosis

Shani Can is a bright-eyed 28 year-old who loves to draw, watch teen movies and paint – like Picasso, her mom says with a smile. Shani has a home she shares with two younger brothers, her mom and dad. She also has I/DD and is nonverbal. Shani came to Achievable recently on a referral. Her family had always been told her disability was due to a difficult birth and lack of oxygen. However, after a full psychiatric and medical review at Achievable, Dr. Mark Benor detected Phelan-McDermid Syndrome, or Deletion 22q13 Syndrome, a genetic condition associated with speech and developmental delays. The correct diagnosis will impact her future care. "I'm amazed the other doctors never detected anything. In two months, we have the right diagnosis for the first time in 28 years. It was a surprise, but knowing has made a big difference. It's really big for our family," says Shani's mom, Germana.

Story of Hope: Can Family Finds Footing with New Diagnosis



continued from page 1

Shani's family experienced similar frustration with other medical issues through the years. Because Shani can't tell anyone how she feels, it's up to her family to guess and advocate for her. A missed diagnosis of advanced cataracts took months of the family insisting Shani was experiencing an issue before she was finally treated.

Unfortunately, this story happens all too often for patients with I/DD. It underscores why specifically trained medical staff are so important in helping patients with I/DD achieve the best quality of life they can.

Germana is thankful her family's short time with the Achievable Medical Center has brought needed testing and screenings that no one knew to do before: an ultrasound because patients with her diagnosis can experience kidney issues; an MRI to screen for fluid in the brain.

"To find doctors like those here is very difficult," says Germana. "When she's with other doctors, they don't really put the time or even care about her special needs. They are in a hurry. Here the doctors are human. They treat people with disabilities with respect and are very kind. And patient."

The family's goal in the near term is getting the right medication to address Shani's behavioral needs, which will lead to less side effects and more peace at home. And they finally have peace of mind that she is getting the right treatment.

The Achievable Gala September 7, 2017

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News from the Field

Our last issue discussed a case before the Supreme Court that would have bearing on special education services mandated in public schools.

Disabled children were guaranteed the right to a "free appropriate public education" with Congressional passage of the 1975 Individuals with Disabilities Education Act (IDEA), but to date, the standard had not been set. The level of this provision has been open to interpretation locally, and therefore, great variances exist.

This case was brought by parents whose son with autism made significantly better progress at a private school than at the public school he'd formerly attended. The parents asserted that the public school didn't go far enough as stipulated in IDEA to create a tailored education plan that addressed his needs. The Court agreed.

In a unanimous decision, they advocated that an "appropriate" education means a chance for children with disabilities to make "appropriately ambitious" progress. "It cannot be right that the IDEA generally contemplates grade-level advancement for children with disabilities who are fully integrated in the regular classroom, but is satisfied with barely more than *de minimis* progress for children who are not," according to the opinion, signed by Chief Justice John Roberts.

We celebrate the advancements this decision could lead to in public schools on behalf of families with children with I/DD. And we applaud the Supreme Court for recognizing that "good enough" is not the same thing as "good" when it comes to something as vital as education.

Foundation Spotlight: Dr. Alicia Bazzano, PHD., M.D., M.P.H.

When Dr. Alicia Bazzano began at Westside Regional Center (WRC) over a decade ago, she quickly discovered that all medical care is not created equal. She regularly saw people with intellectual and developmental disabilities (I/DD) who were underserved or misdiagnosed largely due to communication difficulties. She came across numerous patients with I/DD who had undergone unnecessary procedures, and were not getting the proper preventative screenings that people without I/DD take for granted. She realized that adequate health care for patients with I/DD in some cases may even have prevented untimely deaths.

To address the gap in health services, Dr. Bazzano and her colleagues, Dr. Ari Zeldin (Pediatric Neurologist), and Danise Lehrer (Director of Clinical Services at WRC) began working through Achievable and WRC with health centers like South Bay Family Health Center and Venice Family Clinic to offer services to people with I/DD. However, the demand for appointments for these underserved patients quickly overwhelmed available resources at these health centers.

At that point, Dr. Bazzano, Dr. Zeldin, Ms. Lehrer, and the Board of Directors of Achievable made the audacious decision to start a new health center focused on caring for individuals with I/DD. With Dr. Bazzano and Dr. Zeldin at the helm as Co-Chief Medical Officers, and Danise Lehrer as Achievable's volunteer Executive Director, the team set out to establish the Achievable Health Center as we know it today.

From the start, the Achievable Health Center was designed to attract staff dedicated to providing high-quality care for patients with I/DD, and the health, behavioral and care considerations that go along with that. In those first days, everyone wore many hats in true "start-up" fashion. "We wanted to have a welcoming place and to make sure we were inclusive of people of all abilities," explains Dr. Bazzano. She and her team had to decipher new logistics, from contracting with insurers to deciding on equipment appropriate for individuals with I/DD. Most crucially, they hired dedicated team members, several of whom remain with Achievable today.

As part of the Achievable team, Dr. Bazzano cares for children with developmental concerns. Dr. Bazzano has an emerging focus on developing care plans across the multiple systems families use: school, mental health and Regional Centers. She also continues to educate the community about the needs of people with I/DD through advocacy and teaching.

"It's pretty amazing to see what started out as conversations after work actually functioning as a health center that is improving the health of our community," reflects Dr. Bazzano.



On Thursday, June 15th, Achievable is hosting an exclusive screening of the classic comedy "Airplane!" at the William Morris Endeavor (WME) talent agency in Beverly Hills.

Join us for a private cocktail reception before the screening and an exclusive Q & A session with a select group of cast members to hear behind-the-scenes stories from this sidesplitting comedy!

All proceeds benefit the Achievable Health Center. Contact Josh Kruskol (jkruskol@achievable.org) for more information.

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The Achievable Foundation's mission is to provide high quality, integrated health care to individuals with intellectual and developmental disabilities, their families, and other vulnerable populations.

5901 Green Valley Circle, Suite 405 Culver City, CA 90230-6953 Achievable is hiring medical providers!!

If you are interested in being part of a team innovating a new model of care for vulnerable populations, especially individuals with developmental disabilities, go to our website to apply:

https://achievable.org/contact-us/join-our-team/

Achievable Update: Spring Speakers Forum



On April 6, The Achievable Foundation welcomed local officials, patients, families and advocates to its Spring Speakers Forum.

Culver City Mayor Jim Clark delivered remarks to the assembled group, toured the facility with CEO Carmen Ibarra and presented a donation. The evening's discussion centered around two factors that can lead to a healthy life for individuals living with I/DD: employment and access to health care.

Dr. Pam Wiley, President and Founder of L.A. Speech and Language Center, spoke of the need for those with I/DD to continue social skills training across their lifespan. "The days of 'sheltered workshops' for this population

are over – technology has connected them to the world, and they want to be a part of it," she said. "For that, they need jobs." Social skills training prepares them to navigate the workplace, interact with others and maintain employment, according to Dr. Wiley. Successful training includes interviewing skills, workplace culture, workplace idioms and body talk, she explained. Sustained employment is important in furthering self-esteem, independence, income and socialization.

Cori Racela, a senior attorney at the Western Center on Law and Poverty, explained how vulnerable those who rely on Medi-Cal are in the current political climate. She stated that "state flexibility" in the Medicaid (Medi-Cal) program is code for reduced Federal funding and suggested people stay informed of potential changes to Medi-Cal on the federal level. Those that may be impacted by changes should contact the Health Consumer Center in Los Angeles (800-896-3202), which offers free services to help with Medi-Cal, county programs and Covered California private insurance.

The Achievable Foundation wishes to thank our speakers and attendees for exploring these important topics together.