

# FACES OF MASSHEALTH: PORTRAIT OF A DIVERSE POPULATION

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*Health Care For All*

## **ABOUT THE MASSACHUSETTS MEDICAID POLICY INSTITUTE**

The Massachusetts Medicaid Policy Institute (MMPI)—a program of the Blue Cross Blue Shield of Massachusetts Foundation—is an independent and nonpartisan source of information and analysis about the Massachusetts Medicaid program, MassHealth. MMPI's mission is to promote the development of effective Medicaid policy solutions through research and policy analysis.

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## **ABOUT HEALTH CARE FOR ALL**

Health Care For All (HCFA) is a state-based 501(c)(3) health care advocacy and education organization that advocates for health justice in Massachusetts by working to promote health equity and ensure coverage and access for all. As leaders in public policy, advocacy, education, and service to consumers, HCFA works to create a Commonwealth in which everyone has the equitable, affordable, and comprehensive care they need to be healthy.

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## FACES OF MASSHEALTH: PORTRAIT OF A DIVERSE POPULATION

Serving over 1.8 million Massachusetts residents, MassHealth provides access to health care services for people of varying ages and life circumstances across the Commonwealth. These services improve enrollees' health<sup>1</sup> and enable them to succeed in other aspects of their lives. Through MassHealth, low-income women have access to prenatal care that gives their babies the best chance at a healthy start in life; children with special needs have access to comprehensive health care and the support services required to reach their full potential; young adults are able to pursue higher education and job training to advance their careers without the fear of losing insurance coverage; adults working in low-wage sectors, like restaurants and construction, can provide health security for their families; and the elderly and those living with disabilities receive services and supports that help keep them out of institutions and in their homes and communities.

Gaining a comprehensive understanding of MassHealth enrollees—who they are and what role MassHealth plays in their lives—is critical to informing policy and program development. With the goal of painting a picture of the diverse population served by MassHealth, the Blue Cross Blue Shield of Massachusetts Foundation partnered with Manatt Health and Health Care For All to create a profile of the more than 1.8 million Massachusetts residents enrolled in MassHealth. This profile has two components:

1. A quantitative profile of the demographic and socioeconomic characteristics of individuals enrolled in MassHealth as of June 2018. This analysis is summarized in a separate [chart pack](#).
2. Qualitative profiles, appearing below, of Commonwealth residents whose lives have been impacted by MassHealth. To develop these profiles, Health Care For All reached out to over 100 partners across Massachusetts, including community-based groups, direct-service agencies, and advocacy organizations, to assist in identifying current MassHealth members willing to participate. Health Care For All staff then screened over 60 individuals and families to verify MassHealth coverage status and to select a diverse portfolio of individuals and families to feature. Finally, they conducted in-depth personal interviews and photo shoots with five individuals/families to document the role that MassHealth has played in their lives.

The quantitative chart pack (available [here](#)) paints a picture of the diversity of MassHealth enrollees. They are geographically spread out over Massachusetts; varied in age, from birth through 90-plus years old; majority white but still extremely racially diverse; predominantly female; and mostly very low-income (the majority of MassHealth enrollees live on annual incomes below 86 percent of the federal poverty level at \$10,440 for an individual or \$17,871 for a family of three). While some enrollees are living with disabilities or have high medical needs, others depend on MassHealth to access only routine and preventive care.

The quantitative data provide an overall but abstract picture of the population that MassHealth serves. Behind the data are real people—in diverse life circumstances—whose lives are touched in different and important ways by MassHealth. The remainder of this report is devoted to telling a few of their stories.

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<sup>1</sup> Kaiser Family Foundation. (March 28, 2018.) *The Effects of Medicaid Expansion under the ACA: Updated Findings from a Literature Review*. Available at <https://www.kff.org/medicaid/issue-brief/the-effects-of-medicaid-expansion-under-the-aca-updated-findings-from-a-literature-review-march-2018/>.

## ANNE JOHANSEN

The doorbell rings on the sixth floor of a high-rise apartment building in Quincy. There is a pause before 66-year-old Anne Johansen can get to the door in her power wheelchair. It is one of the first warm days in late spring, and the bright sun and a cool breeze drift into Anne's living room as she sits among her grandchildren's neatly arranged books and toys. In just a few days, Anne will mark six years since she moved into this apartment. It is a day she remembers clearly because, she says, it is the day she regained her freedom.



**Like her mother and younger brother, Anne has Charcot-Marie-Tooth disease (CMT), one of the most common inherited neurological disorders, which affects approximately one in 2,500 people in the United States.**

CMT is a disease of the peripheral nerves that control muscles. It is slowly progressive, causing loss of normal function and/or sensation in the lower legs, feet, hands, and arms. There is no known treatment or cure for the disease. It was in the early 1970s, when Anne was working as a young ward secretary at the Floating Hospital for Children in Boston, that her symptoms first became pronounced. Every morning she commuted on the Green Line and walked to the hospital from Park Street across what was then known as the Combat Zone. "It was a bit of a walk," says Anne. "Boston sidewalks are not wonderfully smooth, and I seemed to find every crack." She recalls, "It was just incredible." Anne commuted with her husband who would put his arm around her to hold her up, but she would still fall, arriving at work with legs scraped and bloodied. Anne soon underwent three consecutive surgeries, after which she was no longer able to navigate her commute to work.

Anne and her husband returned to their native Denver, trying hard to balance the symptoms of Anne's illness with their personal and professional goals. She completed a class to become a medical assistant and took a job at a newly opened clinic. During that time, Anne became dependent on forearm crutches to walk. She persevered as the only medical assistant for three doctors. She loved the work and took every opportunity to advance professionally, and she soon was promoted to work as an aide in the ophthalmology department.

Anne and her husband hoped to start a family. They pursued adoption, but when they informed the agency that she had a progressive neuromuscular disease, they were told they would not be able to adopt. "So we went back to plan A," recalls Anne. "And I got pregnant." She explains with relief that her daughter Elizabeth did not inherit CMT. Meanwhile, the demands of work became untenable in the face of Anne's progressing illness. After moving to a desk job, Anne discovered she was no longer able to type on a manual typewriter. At the age of 27, she had to stop working and applied for Social Security Disability Insurance, which was granted immediately. Dependent on crutches and braces for her mobility, Anne focused on her young daughter. When Anne turned 35, she began using a power wheelchair and soon had to give up driving. **"I probably went for most of Elizabeth's school years getting my own groceries and going around in my wheelchair to get things and do things," recalls Anne. "It was about seeing how much further I could go."**

At the same time Elizabeth graduated from college, Anne's then ex-husband lost his job and, therefore, the employer-sponsored health insurance that had continued to cover Anne. It made sense for Anne, whose

health was worsening, to follow Elizabeth east to Massachusetts. Anne soon discovered she was eligible for MassHealth and enrolled. For seven years Anne cycled from one nursing home to the next. With the help of a friend, Anne learned about the Boston Center for Independent Living and, in turn, applied for Section 8, the federal government's program to assist low-income families, elders, and people with disabilities to afford housing in the private market. While MassHealth does not pay for housing, **Anne was able to use her MassHealth coverage to access the services of personal care attendants (PCAs). With their help, Anne built a new life for herself in her own apartment.** Anne has recently moved to a new apartment in Hanover where she enjoys being closer to her grandchildren.

These days, Anne says, her health has deteriorated, and her breathing is sometimes labored. Nevertheless, she relishes her ability to go outside, to meet a friend nearby, or to visit a local shop. Each morning a PCA arrives to help Anne bathe, dress, fix breakfast, and do small chores around the apartment. In the evening, another aide arrives for a four-hour shift. She makes dinner, helps Anne with projects in the apartment, and readies Anne for bed. "Without my PCAs," says Anne, "I couldn't live alone. They are everything."

## JESSICA OLIVEIRA

**This spring, 28-year-old Jessica Oliveira was able to drop her MassHealth coverage when she transitioned to a job that offers health insurance.** She enrolled in coverage through her new employer, a non-profit organization working to end gender violence and exploitation. Jessica is grateful that MassHealth provided her with health security when she didn't have access to health insurance through her previous job as a medical interpreter for Portuguese-speaking patients at a nearby hospital.

As a medical interpreter, Jessica had anywhere from 20 to 50 encounters with patients. These interactions ranged from translating test results over the telephone to facilitating communication between a provider and a patient during a routine check-up, a surgical procedure, or the birth of a child. Jessica worked primarily with Brazilian patients but also interacted with patients from Cape Verde and Portugal. "It was very personal work," says Jessica. "I was usually in the room or listening in on some of the most vulnerable moments of the lives of the local immigrant population."

Jessica is also the recipient of a 2018 Emerging Writer Fellowship from GrubStreet, one of the nation's leading creative writing centers. The Fellowship provides only two writers per year with tuition-free access to Grub-Street's classes and conferences. She was also recently awarded the 2019 Gish Jen Fellowship at The Writers' Room of Boston. When Jessica is not at work, she is often writing at the main branch of the Cambridge Public Library.

Jessica's 2012 graduation from college with a degree in international relations realized one of the dreams that inspired her parents to immigrate to the United States from Brazil when she was eight years old. **After serving as a corps member in the Teach for America program, Jessica worked at a nonprofit consulting firm.** There her interest in the medical field grew. She considered applying to nursing school or medical school, but wanted a better sense of life on the "front lines" of medicine before making the decision. This is what prompted her to get involved at a hospital, where she got a job as a medical interpreter. As a per diem employee of the hospital, she was ineligible for employer-sponsored insurance of her own, however, she was



covered under the commercial health insurance plan her parents received through her father's employer. When she turned 26, she lost eligibility for coverage through her parent's plan, but she was eligible for MassHealth coverage on account of her low income.

So, Jessica enrolled in MassHealth. When Jessica noticed fluctuations in her weight along with other alarming symptoms, she was able to make an appointment with a doctor. She was diagnosed with polycystic ovarian syndrome, a common condition caused by an imbalance of reproductive hormones. A prescription for an oral contraceptive regulated her symptoms, and Jessica felt relief. **What did being able to access health care services as a result of her MassHealth coverage bring Jessica? "Being able to live without having to worry about my health on a daily basis."**

Jessica valued working directly with the Portuguese-speaking immigrant community in her previous role as a medical interpreter. Now a naturalized American citizen, Jessica says, "I consider myself American and well-adjusted to American life. It was nice to be able to use that experience to help patients who are where I once was." **Reflecting on the recent changes to her health insurance, Jessica says, "I now have the opportunity to have employer-sponsored insurance, and I'm glad that MassHealth was there to provide a safety net when I needed it and to help make the transition seamless."**

## SAL AND KRISTAL GURGONE

Sal and Kristal Gurgone, both 38 years old, live next to a nature conservancy at the end of a small street on the outskirts of Worcester. Their yard is well kept and complete with a swing set and a play area. Inside, the family area is decorated with family photographs. On this cool evening in early fall, four-year-old Ethan is at his grandmother's house, but six-week-old Cooper gurgles and grins in Sal's arms as they come to answer the front door.



Sal works as a partner in his father's welding company. While the business is located nearby, Sal says he spends over 50 percent of his work time on the road going to jobs throughout Worcester County and closer to Boston. Kristal is a teacher by training who spent several years working in junior high and high schools for students with severe behavioral issues.

**Sal's company is a small business and does not offer health insurance, so when Kristal was working as a teacher, the couple received health insurance through her employer. In 2014, Kristal was laid off.** The couple was without health insurance

when Kristal found out she was pregnant with the couple's first child. A counselor at the hospital told them that MassHealth coverage was an option. "The lady suggested we apply for MassHealth because [Kristal] was pregnant, and there was only one person working," recalls Sal. Without access to employer-sponsored insurance, the couple qualified based on their income.

**Since 2014, Sal and Kristal have been covered at different times by MassHealth and by plans through the Health Connector; they currently receive MassHealth benefits.**



The couple describes their family's health care needs as "routine," including primary, maternity, and pediatric care. Sal sees a chiropractor. "It's definitely covered," he says, "which is nice. Because we both benefit from [the chiropractor]—especially me, doing a lot of physical labor. It helps me a lot." Sal adds that being able to go to the chiropractor probably helps him avoid needing more intensive care for pain or injuries that result from the physical stress of his work.

"Thankfully, we're in pretty decent health," says Kristal. Nevertheless, both Kristal and Sal say that their Mass-Health coverage brings them a certain sense of security. "If anything went wrong," says Kristal, "we would have the insurance to cover it. Because the last thing you want to worry about is your coverage if you get sick or your kids get sick." Sal agrees, saying, "If something happens—you break your leg, you hurt yourself, you go to the hospital—you don't have to worry about going or trying to find money to pay whatever it may cost."

**With this peace of mind, Sal and Kristal can focus on their young family and their home.** "We're most proud of family. The house. Just basically keeping our heads above water is really what we're proud of . . . that we're able to do it," Kristal reflects. "And to try to provide our kids what we didn't have when we were younger," adds Sal. "Try to give them a good life."

## AMY KATUSKA

Amy Katuska, 28 years old, considers it her purpose to help people. Sometimes this means assisting friends and acquaintances as they apply for jobs or search for an apartment. Other times, it means tutoring perfect strangers online as they learn English.

Since childhood, Amy has had a passion for learning about foreign countries and different cultures. **"You know," she says, "when I was 12, I had my life path all planned out."** Amy took school seriously, loved learning new languages, and dreamed of working for the U.S. State Department. In 2009, as a college student, Amy founded an international pen pal program for children and teenagers in the United States and Iran. The idea, she says, was to give young people the opportunity to learn about a different country directly from people who live there. "It was pretty cool how much people supported the idea," Amy remembers. "There were some really cool interactions that I saw of kids realizing, 'Hey, this person is just like me!' Once you're familiar with somebody, it's hard to hate them. It's easy to demonize people, but once you get to know them, it's much harder." For several years, Amy coordinated the program, organizing volunteer translators and webmasters as well as about a dozen pairs of pen pals at any given time.



Amy's first psychiatric hospitalization occurred when she was 14. The behavioral health issues with which she has struggled for almost half her life forced Amy to leave college and to put the pen pal program on hold. "It's been a struggle," says Amy. **With diagnoses of major depressive, generalized anxiety, post-traumatic stress, obsessive compulsive, and opioid use disorders, Amy has been in and out of inpatient psychiatric units, partial hospitalization programs, and rehabilitation facilities.** "There's a lot of stuff going on that sort of makes it difficult to address any one thing," says Amy. Currently, she says, her days

are defined by many doctor's appointments that are spread over a significant geographic area on Cape Cod and in Central Massachusetts. Unable to drive, Amy depends on family members for transportation. "There is, most days, a fair amount of time spent in the car," she says.

**Amy receives Supplemental Security Income and has been able to remain on her parents' private health insurance plan as a disabled adult child, with MassHealth as secondary coverage.** On a limited budget, Amy credits her MassHealth coverage with making it possible for her to access the health care she needs to manage her behavioral health issues and the chronic pain that is also an ongoing concern. "I know [MassHealth] brings down all my co-pays," Amy says. She doesn't pay a co-pay to see her therapist, and her co-pays for the multiple prescription medications on which she depends are no more than \$3.65 per prescription. "I can cover that," says Amy. "I can find [that amount] in bottles and go return them, if I need to. If it were \$20 each, I couldn't."

**Amy says that without the coverage that MassHealth provides, she would be unable to access the multifaceted care that has helped her to address her health care needs and reestablish a life focused on helping others.** "Without MassHealth," says Amy, "I'd be left without a lot of the care that I get. And I really, right now, need to be addressing all of it to get anywhere, so [MassHealth] makes it much less stressful."

## MASSIMO REVELIOTTY

When Massimo first came to Franciscan Children's Hospital in Boston, he was four and a half months old and just released from a nearby neonatal intensive care unit. Born prematurely at only 27 weeks, Massimo went into cardiac arrest as doctors attempted a tracheostomy and the insertion of a gastrostomy tube. Oxygen deprivation for an unusually long time caused brain damage. Doctors managed to resuscitate Massimo, but as his mother Angela Carosella recalls, "They didn't really have a lot of hope for him." More than likely, the doctors told Angela and her husband Alex, "this child will be technology dependent his whole life, really won't speak, won't see. The list was just long and dark." Twelve years later, Massimo scampers energetically down the same hospital halls begging his mother to allow him one more video on her iPhone.



**At the time of Massimo's birth, Angela and Alex, a small-business owner, had employer-sponsored health insurance through the large university where Angela worked in fundraising.**

The coverage was "great," says Angela. "We never worried about it. We never questioned it." During the long months in multiple hospitals following Massimo's birth, social workers and financial counselors educated the couple about their insurance options. Angela says she was surprised when they first suggested the family apply for MassHealth coverage as secondary to their commercial insurance. "We didn't think it was for us because we just didn't really understand it. We thought it was for people who don't work, who have



no income.” Then it came time to plan for Massimo’s discharge, and Angela and Alex realized that the home nursing care on which they would depend was out of reach. The family’s commercial insurance would not cover it, and they could not afford to pay for it out of pocket. “We learned what MassHealth really does,” recalls Angela. “We learned that it closes the gap.” **Massimo initially qualified for the Kaileigh Mulligan Program, which provides MassHealth services and benefits to certain children with severe special needs who are over the income limit for MassHealth eligibility and require the same level of ongoing nursing and medical care as a child living in a pediatric nursing home or hospital.**

Massimo’s medical needs have decreased, so he is no longer eligible for this program, but the family continues to have MassHealth as secondary coverage for him. When Angela lost her job—and the employer-sponsored insurance that came with it—several years ago, the family began purchasing its own insurance on the private market. Today they receive premium assistance for that coverage through MassHealth as well.

Massimo’s first years were defined by daily appointments, countless therapies, and multiple inpatient hospitalizations. The little boy depended on a wheelchair, supplemental oxygen, a speaking device, special formula, and durable medical equipment such as a bed, walker, and car seat. Today he not only walks, talks, and eats on his own, but he also plays adaptive sports, collects toy cars, and loves math problems. Soon, with the help of an aide, Massimo will complete fifth grade in a public school classroom. Almost every day after school, Massimo attends medical appointments or speech, occupational, or physical therapy. This afternoon, he is on his way to Lego Club, a therapeutic social group.

When Angela reflects on the seemingly boundless progress Massimo has made, she focuses particularly on the family’s ability to pursue every test and treatment that has been recommended along the way. “Of course we would have pursued every option to save Massimo, but it’s because of MassHealth that we were able to stay laser-focused on taking care of our child, evaluating options, and not worrying about how we were going to pay for it,” says Angela. Throughout, the family’s secondary MassHealth coverage has picked up where their commercial coverage left off, paying for procedures and services not covered by the primary insurer and covering co-pays. “That can get pricey,” Angela says of co-pays. “Five days a week at 40 bucks a pop adds up quickly.”

**Massimo’s progress is ongoing, and his future is bright. “I want to work with traffic when I grow up,” he announces as he races a small yellow convertible toy car across the table.** As Angela lists the tests, specialists, treatments, equipment, and therapies, she describes them as tools that helped build Massimo’s life to where it is today. “MassHealth was there when we needed it,” she says. Angela then remembers that Massimo still depends on inserts in his shoes that help him walk. “MassHealth pays for that,” she says. But then she explains that soon Massimo won’t need them anymore.



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