

Breathe Easy Narratives



This document contains a collection of fictional narrative vignettes — short, character-driven stories grounded in real data on health disparities — developed to support the *Design Care Delivery Transformation Presentation*. Each vignette opens with a disparity statement drawn from published research, followed by a narrative that humanizes the data by following a fictional individual navigating the healthcare system.

Facilitators should select one, two, or three scenarios in advance and distribute them to small groups during the activity.

How to Use These Vignettes:

Each story is an entry point for applying the session's core tools and frameworks. After reading a vignette, participants should consider:

- What root causes are driving the health or healthcare inequity this person is facing?
- How do structural racism and social determinants of health show up in this story?
- What would a priority matrix look like for this scenario?
- How would you design a care delivery transformation to address this situation? What levels, strategies, and modes would you use?

Participants are encouraged to sit with the complexity of each story before jumping to solutions — the goal is not just to identify an intervention, but to understand *why* it is needed and *for whom*.

Vignette 1:

Between 2016 and 2021, there were 23,550 asthma-related Emergency Department (ED) visits among Chicago youth 19 years old and younger. Most of those visits, 70% (16,436), were among school-age youth 5-19 years. In total, Black children accounted for 53% of 16,436 asthma-related ED visits. In children 4 years old and younger, 40% of visits were by Black children.¹

Sean is a Black 10-year-old boy who lives in the Back of the Yards neighborhood in Chicago, Illinois. Sean was diagnosed with asthma at the age of 5. Within the last year, Sean has been having worse and more frequent asthma attacks that have resulted in numerous visits to his local hospital's emergency department.

Sean lives with his 6-year-old sister and 4-year-old brother, and his mother, Nicole, age 35. Nicole has been struggling with her own medical care and management. After Sean's parents divorced two years ago, his father moved to Michigan. Although the kids spend summers, spring break, and holidays with

¹ "Racial Disparities in Childhood Asthma Chicago, 2016-2021," *Respiratory Health Association*, May 2022. <https://resphealth.org/wp-content/uploads/2022/05/Updated-Asthma-Disparities-Report.pdf>

their dad, Nicole does most of the day-to-day childcare on her own, with occasional help from neighbors or her brother, who lives an hour away. Even with financial help from her ex-husband, Nicole's finances are still stretched. Nicole often prioritizes her kids' immediate needs over her own long-term care. As a result, her diabetes is uncontrolled and has resulted in her developing hypoglycemia, peripheral neuropathy, and high blood pressure.

Nicole's escalating medical needs have made it increasingly difficult to hold down a job. Income insecurity limited the family's options in finding a safe and healthy home; she compromised on an affordable rental unit in poor condition that is within walking distance of a public library and Sherman Park, a 60-acre space filled with wildlife trails and places to enjoy nature. Because of the neighborhood's relatively high crime rate, however, Nicole and her ex-husband decided that the kids must be with an adult when they're outside. That means the kids spend more time indoors when Nicole isn't feeling well.

Nicole suspects that the conditions in their home are exacerbating Sean's asthma, so she scheduled an appointment to see Sean's doctor. However, between losing her job, providing for her 3 kids, managing her health needs, and managing her kids' health needs, Nicole is often overwhelmed. She missed the last 2 of 3 appointments with Sean's doctor and the office is less inclined to schedule her for appointments, often putting her on a waitlist. Nicole considers her options and knows that any medical attention is better than none. She starts taking Sean to the local hospital's ED because it's the only way she can manage to get Sean any medical attention and refill his prescriptions in a timely manner.

Vignette 2:

Research shows that undocumented immigrants are more likely to report greater depression and social isolation, higher rates of hypertension with longer length of hospital stay, greater anxiety and post-traumatic stress, and higher levels of acculturative stress compared to documented immigrants.² Approximately 7% of the population in Chicago, Illinois, is undocumented.³ Latin American immigrants make up approximately 85% of Chicago's undocumented population.⁴

Luis and Ana migrated to Chicago, Illinois, from El Salvador after a devastating earthquake in 2005 left most of the region severely damaged. Chicago was an easy choice to make. They already had extended family in the city, which would help them and their 1-year-old son, Jaime, get on their feet and acclimate to life in a new country.

Fast forward eighteen years and Jaime will soon turn 19. A bright and happy teenager, Jaime is an autistic person who is non-verbal, g-tube dependent, and has diabetes. As a result of his medically complex needs, Jaime requires frequent and consistent managed care to keep him healthy. Jaime has been able to receive medical care through the state Medicaid program, however, his coverage is expected to lapse once he turns 19; he will no longer be eligible for the state's health insurance program.

The provider Jaime has been seeing for the last 10 years speaks fluent Spanish and knows Jaime and his family very well, but she is not able to continue providing care to him without coverage. Although

² Consuelo Arbona, Norma Olvera, Nestor Rodriguez, Jacqueline Hagan, Adriana Linares, "Acculturative Stress Among Documented and Undocumented Latino Immigrants in the United States," *Hispanic Journal of Behavioral Sciences*, vol. 32, no. 3 (2010): 362-384. <https://doi.org/10.1177/0739986310373210>

³ Rob Paral, "Illinois' Undocumented Immigrant Population: A Summary of Recent Research," Illinois Coalition for Immigrant and Refugee Rights, February 2014: 2. <https://robparal.com/wp-content/uploads/Illinois-Undocumented-Immigrant-Population.pdf>

⁴ *Ibid.*, 4.

Luis and Ana speak English at work and with Jamie's care team, they feel more comfortable hearing medical terminology and instructions for Jaime's care in Spanish. As Jaime's birthday nears, his parents grow increasingly worried. Jaime is at acute risk for complications. Every missed appointment exacerbates their fears he will become deathly ill.

However, undocumented immigrants are largely ineligible for federal healthcare programs like Medicare and Medicaid. Although federal legislation requires hospitals receiving Medicare funding to provide emergency care for all regardless of citizenship status, it does not offer reimbursement for nonemergency services and care to undocumented patients.⁵ As a result, undocumented immigrants have significantly limited access to healthcare, especially routine preventative healthcare. Jaime's family is now tasked with finding a care team that will provide care to an uninsured person and coordinate the required specialized care that Jaime needs.

Vignette 3:

Transgender and gender non-conforming people frequently experience exclusion and discrimination in healthcare settings.⁶ In a national survey of transgender discrimination in healthcare in the United States, researchers found that 28% of respondents reported postponing needed medical care because of fear of discrimination.⁷ In the same study, 19% reported being refused care because of their gender identity; 28% reported being victims of physical violence in medical settings; and 50% indicated they had to educate their medical provider about basic information regarding transgender individuals.⁸

Ven is a 24-year-old trans woman who relocated to Jacksonville, Florida, when she accepted a job offer as the lead IT Security Specialist for a major international corporation. Ven lost her mother to breast cancer in the past several months and has since been worried about her own health given her family history. However, Ven has to find new healthcare providers in her new town before she can get a cancer screening. She also needs to find a doctor who will update her hormone and anti-anxiety medication.

Unfortunately, Ven's most recent experience with a new provider made her hesitant to return. During her last visit, the staff repeatedly misgendered Ven despite her correcting them multiple times that she uses she/her pronouns. Furthermore, despite her express desire to be screened for breast cancer, the provider dismissed her worries because he doesn't have much knowledge or experience with trans health. Frustrated, Ven asked if the doctor could make a referral to another office with more experience with transgender patients, but the doctor was again unhelpful and suggested Ven try to find one herself.

In the end, Ven left the appointment angry, disappointed, and frustrated. Ven's anxiety around getting care has only gotten worse. It has been several weeks since she's seen a doctor and she is running out of her medication. She continues to grow anxious about her health.

⁵Sawyer NT. Why the EMTALA Mandate for Emergency Care Does not Equal Healthcare "Coverage". West J Emerg Med. 2017 Jun;18(4):551-552. doi: 10.5811/westjem.2017.5.34826. Epub 2017 May 15. PMID: 28611872; PMCID: PMC5468057.

⁶Kristie L. Seelman, Matthew J.P. Colón-Díaz, Rebecca H. LeCroix, Marik Xavier-Brier, and Leonardo Kattari, "Transgender Noninclusive Healthcare and Delaying Care Because of Fear: Connections to General Health and Mental Health Among Transgender Adults," *Transgend Health* vol. 2, no. 1 (2017): 17–28. doi: 10.1089/trgh.2016.0024

⁷Jaime M. Grant, Lisa A. Mottet, and Justin Tanis, "National Transgender Discrimination Survey Report on Health and Health Care," October 2010. National LGTQ Task Force. https://cancer-network.org/wp-content/uploads/2017/02/National_Transgender_Discrimination_Survey_Report_on_health_and_health_care.pdf

⁸Ibid.