5-2022

In the Well A Social Media Communication Pilot to Engage and Educate the Public on Health Care Systems and Policies

Debra Dunlap

In the Well

A Social Media Communication Pilot to Engage and Educate the Public on Health Care Systems and Policies

Debra Dunlap, MPH Candidate
Faculty Advisor Dr. Erika Ziller, PhD

4/28/22

Muskie School of Public Service
Master Public Health Capstone

Contents

Overview

The purpose of this capstone project was to engage the general public to think and learn about health care systems and the policies and public opinions that influence them. The project developed a method of public engagement and education by establishing a new social media blog titled *In the Well,* and piloting four posts and companion recordings. A brief impact study was conducted to assess the effectiveness of this communication method, and to answer the key question: are the project's social media posts an effective method for engaging and educating people to think about health care systems and policies?

Rationale

Public opinion has a direct influence on the success or failure of healthcare policies. As Deborah Stone observes in her book Policy Paradox, "because politics and policy can happen only in communities, communities must be the starting point" (2012). Recognizing the importance of engaging communities in public health policymaking, the U.S. Centers for Disease Control and Prevention include Stakeholder Engagement and Education as an overarching domain in their Policy Process (U.S. CDC, 2021).

The global Covid-19 pandemic has provided an opportunity to engage the public in health policy conversations in ways that are more relevant and critical than ever. There is evidence that public opinion in America continues to shift toward favorable views of health system reforms, including universal healthcare, and support has increased during the pandemic (Kaiser Family Foundation, 2020). However, the American healthcare system is complex and difficult for most citizens to understand (Brega, et.al., 2015), and public conversations about health systems reforms are dominated by healthcare leaders and political operatives. Members of the public are heavily influenced by the way conversations are framed (Jones, 2020), and it is difficult to find spaces that encourage citizens to develop a collective vision of the type of healthcare systems they would like to have in America. Despite these challenges, public health practitioners have a duty to “study and also change” the public conversation about our systems of care, and finding ways to do this successfully is critical (Galea & Vaughn, 2018).

There is a significant body of literature about the role of public health professionals in contributing to public conversations that shape healthcare policies. In 2018, Galea et. al. published a call to action in the American Journal of Public health, noting “our norms and broader public conversation that influence them are an unavoidable cause of population health. A public health of consequence must recognize this and consider both how we may study and also change such a conversation. Training the next generation of population health scholars and public health practitioners to do just that stands to move us in the right direction.”

Literature also emphasizes the important role of engaging the public in healthcare improvement efforts. The Institute for Healthcare Improvement’s Triple Aim initiative focuses on patient experience of care, and requires that “the population served become continually better informed.” One of the authors of the Triple Aim initiative has observed that moving to a true patient-centered care model requires shifting control and power out of the hands of those who give care and into the hands of those who receive it (Berwick, 2009).

Research has also identified many challenges to engaging the public in true system reform efforts. National surveys have shown the majority of American adults (88%) do not have the necessary health literacy skills to understand and manage all of the demands of the current

HEALTH LITERACY IS “THE DEGREE TO WHICH PEOPLE HAVE THE CAPACITY TO OBTAIN, PROCESS, AND UNDERSTAND BASIC HEALTH INFORMATION NEEDED TO MAKE APPROPRIATE HEALTH DECISIONS” (RATZEN ET. AL., 2000).

health care system (Brega, et. al., 2015). There is substantial research demonstrating the importance of employing health literacy principles including plain language in all communication related to health and health care systems (Institute for Healthcare Advancement, n.d.).

Social media can be an accessible way to educate and engage the general public about health and healthcare issues (Osborne, 2018). Yet a 2019 review of efforts to use media to impact health policy-making by Bou-Karroum et.al., found "a lack of reliable evidence to guide decisions on the use of media interventions to influence health policy-making." The authors identified the need for more research "to better understand the effects of media interventions, particularly social media, on health policy-making processes, and the circumstances under which media interventions are successful."

This project conducted a review of health-related social media blogs and podcasts in the U.S. and identified three focus areas: health policy by and for healthcare and policy professionals; healthcare cost and waste; and "expert" advice on improving personal health.[1] The review did not identify any social media specifically seeking to engage the general public to think about health care systems and the policies and public opinions that influence them.

Methodology

This project developed a pilot method of public engagement and education by establishing a new social media blog titled *In the Well*, and launching four posts with audio recordings. Blog posts combined personal human interest stories with factual healthcare system and policy information. A brief impact study was conducted to assess the effectiveness of this communication method. Survey questions measured interest in the topic, relatability of the blog posts, and respondent perspective about the impact of public opinion on healthcare policy.

---

[1] Details of this review are in Appendix A.

Figure 1. U.S. CDC Policy Process

The conceptual framework that was used to guide this method was the U.S. Centers for Disease Control and Prevention Policy Process in Figure 1 (U.S. CDC, n.d.). This framework includes Stakeholder Engagement and Education as an overarching domain that should be implemented during each step of the policy process, including "identify(ing) and connect(ing) with…those affected by the policy, and the general public…; implementing communication strategies that deliver relevant messages and materials; and soliciting input and gathering feedback" (U.S. CDC, n.d.). Health Literacy principles were also applied, including plain language and universal precautions, including audio recordings of each post (Brega, et.al. 2015).[2]

The *In the Well* blog was developed and launched on the Blogger platform, one of the longest-running blog platforms in the U.S. (Hyber, 2021). This platform was chosen for the ease of creating a new blog with no website fee. The following purpose was posted on the blog site: "Public conversations about health care in America are dominated by powerful leaders and politicians. This series explores health and treatment the way we do in our own lives: by focusing on personal stories and experiences. Through topics like disability, mental health, and how we pay for care, we will look at some of the reasons why our healthcare systems are set up the way they are, and times when they have been changed to work better for the people they serve." Four human interest stories were developed with factual health information that was backed by research and historical documentation. Based on restrictions in the survey method,

---

[2] The timeline and advisory team for this project is in Appendix B.

the word count for each post was limited to 600 words or less. Topics for the four posts were community health context; disability care; treatment for mental health and substance use disorders; and crowdsourcing methods of payment for healthcare. Audio recordings were included in each post.[3]

Survey questions were developed at the beginning of the project to collect preliminary information on the efficacy of the project's use of social media posts to engage and educate the general public on health systems and policies.[4] Subjects were randomized respondents through online surveys distributed by the paid Survey Monkey Audience service. Primary source data was collected through a random sample of 150 completed surveys through the fee-for service Survey Monkey Audience.[5] The Survey Monkey Audience sample was U.S. All Regions; Gender Both- Balancing Census; Age 18-99- Balancing Basic Census; Income 0-200k+.[6] Subjects were asked to read or listen to the four blog posts, then asked if the information was familiar to their own lives, if they learned anything new, if they would share the post on social media, and how much of an influence they think public opinion has on healthcare systems. The survey used quantitative Likert scale questions and included one open-ended narrative question for qualitative feedback. Data were analyzed using Excel spreadsheets and analytic features on the Survey Monkey platform. Convenience sampling was also used to collect brief narrative feedback on the blog website from people within personal networks of the principal investigator who interacted with the full platform. This was necessary due due to the limitations of the Survey Monkey Audience service, which did not allow an active link to the blog website in the surveys, limiting feedback to content of blog posts that were copied directly into the survey.

---

[3] Post content and blog website URL in Appendix C.

[4] The Office of Research Integrity and Outreach (ORIO) evaluated information provided in a Request for Determination of Research Involving Human Subjects and subsequent correspondence, and determined that the activities of this project did not involve human subjects.

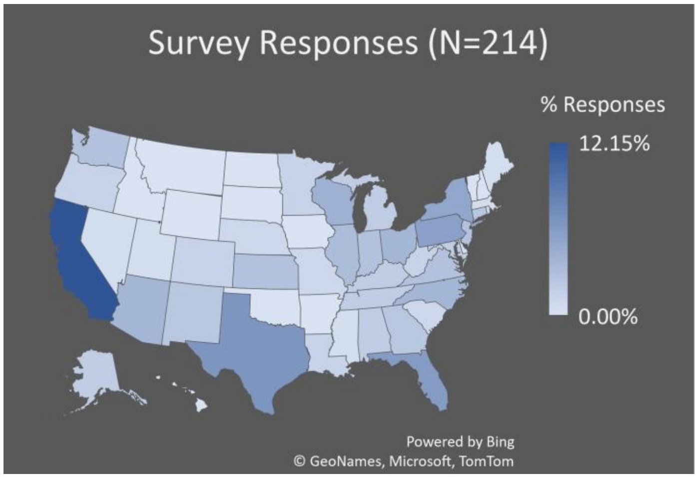
[5] A total of 214 surveys were returned through the paid service to meet census balancing parameters.

[6] Demographics of survey respondents are in Appendix D.

Results

A total of 214 surveys were completed by respondents in 39 states. Overall response to the blog posts was positive. 50% of respondents reported they were extremely or very interested in the blog after reading the first post; 32% were somewhat interested; and only 18% were not so or not at all interested.

Figure 2. Survey Response by State

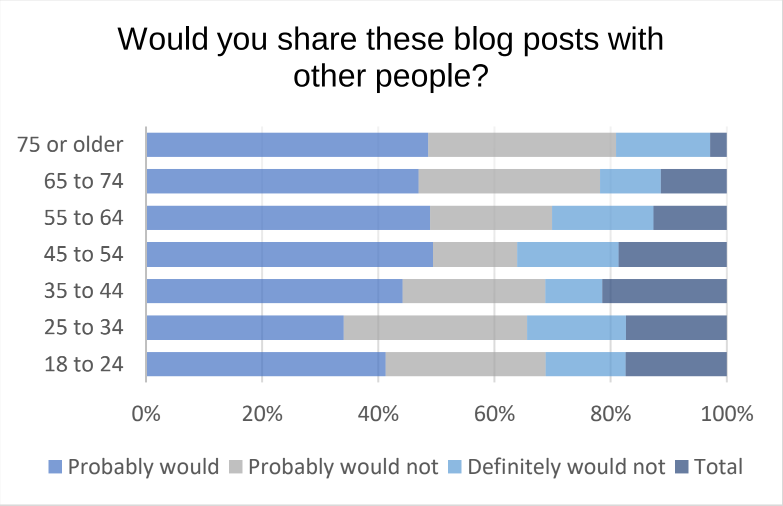


Responses were favorable toward the method of combining personal human interest stories with factual information about healthcare systems and policies. Several narrative responses spoke specifically to this approach: “The first blog post was written from an impersonal ‘we’ perspective and felt institutional and formal and uninteresting. The later posts shared a more personal story and were much (sic) interesting.” Another respondent shared, “I think the post about Down Syndrome stood out to me the most; I have a personal connection to the topic and I also think the way that it was written was the most compelling.”

The post that respondents related to the most was the topic of crowdsourcing methods of payment for healthcare, with over two thirds of respondents (68%) reporting this topic was somewhat, very, or extremely familiar to their personal experiences. The post about mental health and substance use treatment was the second most relatable, with 65% reporting the topic was somewhat, very, or extremely familiar. The post about disability topics was the least familiar to respondents, with 45% reporting the topic was not so familiar or not at all familiar to their personal experiences; this was also the post with the highest rating for learning, with 42% reporting learning a great deal or a lot from the post. The other posts (community context, mental health, and crowdsourcing) all had responses within a range of 70-75% reporting learning a moderate amount, a lot, or a great deal from the post, and 25-30% reporting they learned a little or none at all.

One important measure of success for a social media project is the probability that it will be shared widely, and this result was generally favorable. When asked if they would share these blog posts with their social media networks, 61% of all respondents said they definitely or probably would share the posts on social media, while 39% of all respondents said they probably or definitely would not share the posts. One respondent who would share posts commented, “these were excellent articles with both real-life examples and historical facts. The issues presented impact all of us. This is a blog I would read.”

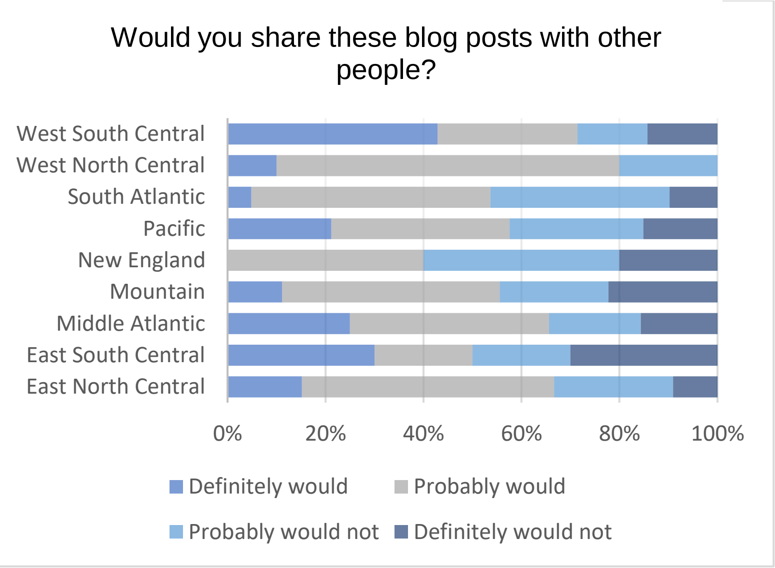
Table 1. Survey Results by Age



Data trends for sharing were also analyzed based on gender, age and region. Females (67%) reported being more likely to share than males (56%). Respondents who reported being the most likely to share were aged 35-44 (67%) and 45-54 (69%). Respondents who reported being the least likely to share were aged 25-34 (53% probably or definitely would not share) and over 75 (50% probably or definitely would not share). Narrative from some 25-34 year old respondents included feedback that the posts were “insightful” but also “boring” and “too much to read…makes it harder to relate to.” “They're good stories but won't appeal to today's fast pace (sic) trend. Need something that stands out.” Respondents over 75 shared personal healthcare stories in comments and one noted, “it say(s) what everyone knows healthcare is just politics.”

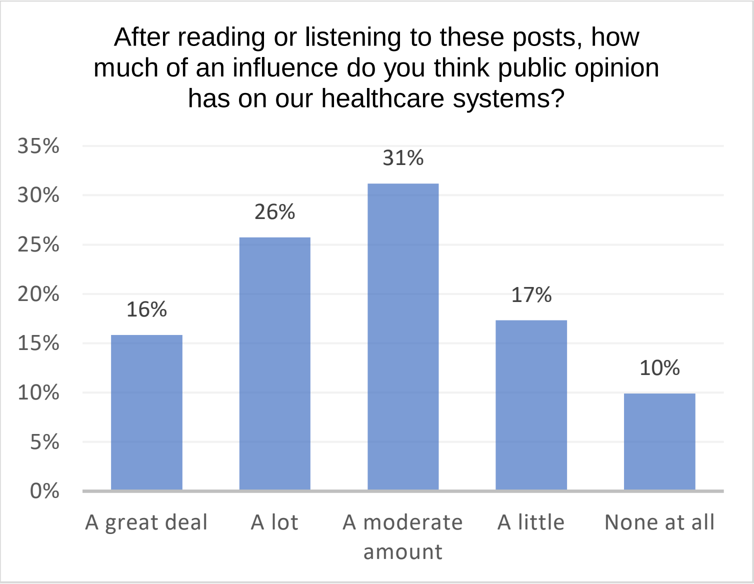
Regionally, respondents who reported they were most likely to share were from the Midwest in the West North Central division (80% definitely or probably would share) and the West South Central division (over 71% definitely or probably would share). Regional respondent groups who were least likely to share included those from New England (60% probably or definitely would not share) and the East South Central region (50% probably or definitely would not share).[7]

Table 2. Survey Results by Census Region



Finally, respondents were asked to share how much of an influence they thought public opinion has on healthcare systems. After reading the post content, only 27% of respondents said they thought public opinion had a little or no influence at all on healthcare systems. Most respondents said they thought public opinion had a moderate influence on healthcare systems, with 31% reporting they thought public opinion had a moderate amount of influence, and 42% reporting a great deal or a lot of influence.

Table 3. Public Opinion Survey Results



---

[7] Map of census regions in Appendix E.

Some respondents expressed frustration with the healthcare system and doubt that public opinion matters to policy makers. “I just agree that our health system may have come a long way since the 50s & 60s, but its stalled.” “Even if the American people rose up and gave a resounding and collective cry for universal healthcare, the government (senators and congressmen and women) will only make it look like they care for a short while before it’s thrown on the back burner and forgotten. They have done this many times before, because they don’t care about the peoples needs as theirs are already taken care of.”

Narrative comments demonstrated active engagement with the topic, one of the goals of the project, and represented a range of experiences and opinions, including both support and opposition to universal healthcare. Many respondents expressed a desire for healthcare reforms. One respondent commented, “I don’t know exactly what this survey is for but I hope it starts a movement.”

Figure 3. Narrative Survey Results

The Healthcare system in the states is broken and corrupt. It needs regulations and affordabilities to everyone but not just for poor.

I owed the hospital because I was desperately ill and had no insurance. That is a travesty.

I work in the healthcare field and fight with insurance companies every day. They do everything they can no to pay.

I don’t believe that universal health care is the answer. This would cause long wait for needed surgical procedures. Who is going to pay for it?

I'm always in medical debt. I can't work because I get state insurance that covers everything an employer based insurance wouldn’t. we need change!

America is the supposed leader in just about everything and I don’t understand why Healthcare is so controversial.

The US (is) driven by big business and money. The rich do not want to care for the weakest in our communities.

I am very dissatisfied with the high cost of healthcare and the little emphasis on prevention from an early age

There are several limitations to these results. Surveys may have measured existing trends across age, geography, income, and gender that were unrelated to individuals reading the blog posts. Results are from a small sample of individuals who are aware of and actively involved in the Survey Monkey Audience process, which may not be a common experience.[8] While survey respondents were not paid for completing surveys, they were incentivized with a donation to the charity of their choice for completing the survey (Survey Monkey, n.d.). Participation in this survey tool implies the population sample all had a moderate to high level of access and comfort with technology, and a willingness to complete surveys for charitable donations. The Survey Monkey Audience tool collected data based on US Census Regions[9] and the highest percentage of responses were from California. There were no responses from states within a large section of the northern Mountain region including Idaho, Montana, Wyoming, North Dakota, and South Dakota. There were only a few responses from states in New England.

The survey tool also prohibited active links to outside pages. The survey included URLs that could be copied and pasted into a new page, but traffic on the blog did not increase on March 30, 2022, the day the Survey Monkey Audience process was initiated and completed, indicating no respondents accessed the blog platform or audio recordings. These conditions limited survey responses to the content only. The survey layout did not follow health literacy principles the blog addressed with audio recordings, white space, font size, visuals, and active links to background information. One narrative response addressed accessibility, noting the posts were “to (sic) long and difficult to finish for my reading attention span.” Feedback on the blog website from a small (N=10) convenience sample of people within the principal investigator’s personal networks reported page layout, use of white space, ease of navigation, and audio recordings made the blog website accessible for their varied reading and attention needs.

---

[8] Members of the project team, including the principal investigator, had little to no experience with Survey Monkey Audience prior to this project.

[9] Map of US Census Regions in Appendix E.

Conclusions

Results from this pilot project indicate the use of blog posts that combine human interest stories with factual healthcare information may be an effective method for engaging and educating some members of the general public to think about healthcare systems and policies. Any future work with this method should explore ways to improve effective communication with audiences aged 25-34 and those over age 75. Considering the cumulative nature of social media communications, future work using this method would also benefit from partnership with existing social media platforms where large target audiences may already be engaged. Any projects using this method should include experts in social media processes on the team to support the continual promotion and refining of content.

Figure 4. Narrative Survey Results

I learn new information

It makes you think

Muy bien bendiciones

They were informative. They make you think.

important investigative topics. would prefer more of an advocacy approach rather than simply informative human interest

They had valid points to share with others

Interesting to think about health care and social opinions

Thank you for working to spread awareness of these important issues!

Appendix A

Table 4. Healthcare Related Social Media Review - January 2022

Health Policy for Professionals	Expert Advice on Personal Health
Podcasts • KHN What the Health https://khn.org/news/tag/what-the-health/ • Tradeoffs https://tradeoffs.org/ • Politico Pulse Check https://politicos-pulse-check.simplecast.com/ • America Dissected- How science, policy and culture shape health. https://crooked.com/podcast-series/america-dissected/ Blogs • Health Related Blogs on Substack were divided between health policy for professionals, personal wellness, and expert education https://substack.com/discover?utm_source=menu-dropdown	Podcasts • TED Health- Smart daily habits to medical breakthroughs, how we can live healthier lives https://www.ted.com/podcasts/ted-health • The Model Health Show https://podcasts.apple.com/us/podcast/the-model-health-show/id640246578 • The Ultimate Health Podcast https://podcasts.apple.com/podcast/id921854276?ls=1&mt=2 • Many Educational/Expert Model/Tip-Based on Nutrition, Fitness and Training, and Personal Growth and Well-Being Podcasts. List of 25 from Healthline here. List of 74 from NPR here. • Fox News had no specifically health-related podcasts. Lifestyle came closest, occasionally covering health issues. Blogs • NPR Shots- Health stories produced by Science Desk, most focused on personal wellness • NYTimes Well- Q&A between readers and medical experts • Most Health-Related Blogs that came up in Google searches were focused on personal wellness. Lists here: https://detailed.com/health-blogs/ and here: https://tinytrips.com/articles/best-wellness-blogs • Health Related Blogs on Substack were divided between personal wellness, expert education, and health policy for professionals https://substack.com/discover?utm_source=menu-dropdown
Healthcare Costs	
Podcasts • Arm and a Leg https://armandalegshow.com/ Blogs • NPR Shots- Health stories produced by Science Desk, some stories addressed costs	

Appendix B

Advisory Team

- Erika Ziller, Ph.D., Chair and Associate Professor Public Health, Director of Maine Rural Health Research Center, Muskie School of Public Service, Portland ME
- Tiffany Greco, LCSW, VP of Learning, Texas Alliance of Child and Family Services, Austin TX
- Sarah MacLaughlin, LSW, Author, Senior Writer for HealthySteps, ZERO TO THREE, Nat'l Program
- Katey Branch, MS, Community Engagement Convener, Artist, South Paris ME
- Reverend Barbara Prose, Executive Minister, All Souls, Tulsa OK
- Amy Pruett, Tech Industry Leader, Chief of Operations, SoCreate, San Luis Obispo, CA

Table 5. Project Timeline 2022

Task	**January**		**February**		**March**		**April**	
	1-23	24-31	1-15	16-28	1-15	16-31	1-15	16-30
Conducted review of healthcare related social media	**X**							
Researched, selected and developed social media platform	**X**	**X**	**X**					
Selected 3-5 health topics	**X**	**X**						
Developed survey questions and collections process	**X**	**X**						
Submitted and completed Request for Determination process		**X**	**X**					
Researched and wrote posts		**X**	**X**	**X**	**X**			
Recorded audio			**X**	**X**	**X**			
Launched blog posts					**X**			
Collected survey results						**X**		
Analyzed survey results						**X**	**X**	
Developed final report							**X**	**X**

Appendix C

The following blog posts and audio can be accessed at https://inthewell2022.blogspot.com/

Post 1: What's In the Well?

Let's start with a story about a man named John Snow (not the king from Game of Thrones, but still important). In 1854, in the Soho Neighborhood of London, there was an outbreak of cholera. Cholera is a serious disease of the intestines that can cause death within hours of the first symptoms. Hundreds of people in the neighborhood were getting sick and dying, and doctors believed the disease was caused by something they called "miasma," or "bad air."

John Snow was a young doctor in London. He had been working on a new theory that cholera was spread through the mouth, not the air. He got a map of the Soho neighborhood and plotted out all the homes where people were sick or had died from cholera, and he found something they had in common: they all got their water from the same well on Broad Street.

John went to the well and looked in. He took samples of the water, talked to neighbors, and was convinced the outbreak was coming from the well. He went to city leaders and talked them into removing the handle from the pump so people couldn't keep using the water. When the handle was removed, the cases of cholera immediately slowed and then stopped.

Over time, more research showed that cholera is in fact spread through contaminated water, proving that John Snow was right. His decision to get close to the problem, to walk into the neighborhood, look at the water, and ask, “what is in this well?” was an important moment in history. And it gives us the framework for looking at the big picture around health.

Most of us don’t spend a lot of time thinking about our own health or medical care until we face issues that make it impossible to ignore. At one point or another, our own or our loved ones’ health comes into sharp focus. Illness, aging, and disability are part of the human condition, and when they show up, they demand our full attention. These days, a global pandemic has many of us thinking and talking about our individual and collective health in ways that we would not have imagined a few years ago.

Most Americans agree that our health care systems are deeply flawed. The ways they are set up are difficult for most of us to navigate. Too many people don't get the care they need. But public conversations about changing these systems to work better for everyone are dominated by powerful leaders and politicians. When our news and online media talk about health, they tend to focus on just two areas: tips from experts (or folks claiming to be experts) telling us ways to improve our own well-being; or policy talk by health care insiders. It is hard to find places where citizens are encouraged to think about the types of care we would like to have for ourselves and our loved ones.

This blog will explore healthcare the way we do in our own lives: by focusing on personal stories about health and illness, what people care about most when faced with these issues, how public opinion shapes and changes our institutions, and how these things connect to the health care systems we have in America today.

In these posts, we will explore topics like disability, mental health, and how we pay for our health care. We will take a look at some of the reasons why our health care systems are set up the way they are, and times when they have been changed to work better for the people they serve.

Our goal is to go out into our own neighborhoods, look into our collective well of experiences, and see what we find.

Post 2: A Look at Disability Care

On the first day of summer in 1995, our son was born with Down syndrome. As this surprising news was shared among our family and friends, the most common response was worry that he would have an unhappy life. When we told our son about this many years later, he laughed out loud. He enjoys telling this story, and reassuring his audience that his life is very happy.

Our worries at the time of his birth were not unfounded. In 1995, the Americans with Disabilities Act was just five years old. Institutional care for people with disabilities was still common. Our state was in the process of closing its largest institution for people with developmental disabilities, formerly known as a home for the “feeble minded,” in response to legal action after decades of resident abuse and neglect. The last resident moved into her new community home as we celebrated our son’s first birthday. It would be three more years before the Supreme

Court delivered the 1999 decision that required all public entities to provide community-based services for people with disabilities because “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

Our son and his peers were the first generation to fully benefit from a home and community based system of care for people with disabilities. They grew up in neighborhoods with parents and siblings, received quality health care from family doctors and specialists, participated in sports and social activities with help from Behavioral Health Professionals, learned how to navigate the community safely, developed essential work skills, and built life-long friendships. Now in their late twenties and thirties, many of them have graduated from college, live in their own apartments, have jobs, volunteer, and own businesses. Their successes are inspiring, but they are not accidental; they are the direct result of three decades of access to home and community based services and resources.

Families and friends of people with disabilities in the decades before our son was born fought hard for the changes in the health care system that have made his independent life possible. Parents refused to place their children in institutions and asylums and advocated for home-based services to help with their care. They fought for equal access to medical treatment and speech and physical therapies. They demanded that schools provide their children with the same opportunities to learn and be part of the community. Our son’s success - and happiness - are a direct result of the work of these families and advocates.

And there is still more to be done. Home and community based health care services are not fully funded, and staff are underpaid. There are long waitlists. We are still working to change the long held belief that people with disabilities, and their service providers, are less worthy of community investments. When these challenges get discouraging, it is helpful to look back and remember that if I had been born with Down syndrome, doctors would have directed my parents to place me in an institution. We have come a long way, and the work continues.

Post 3: Not a Moral Failing

In the late 1940's, my young father's landlords became his legal parents. His parents had separated, and his mother's use of alcohol to cope with her depression made her unable to safely care for him. My father was fortunate that his mother was renting the second floor apartment from Helen and Joe. They had recently lost their adult son in a tragic accident, and they lovingly assumed care of my father for the rest of his childhood. Neighbors said my father was the best thing that could have happened to them.

Unfortunately, the neighbors were not so supportive in other ways. The concept of mental health was not understood, and the social consequences of my grandmother's depression and alcohol use were unforgiving. The youth baseball coach told my father he could not play on the team because his mother was "immoral." There were no accessible treatment options for my grandmother, as her condition was still undefined by the medical profession. Social shame was applied liberally by people all around her in attempts to "make her change." My father would only see her a few times over the rest of her life.

My grandmother's story reflects the medical and societal views of mental health and substance use disorders at the time. Today, we know that one in five Americans experience a mental illness each year, and one in fifteen experience both a mental illness and substance use disorder. These numbers have stayed relatively consistent over many generations. But our country has a long and complicated history of care for people who are experiencing depression or struggling with substance use.

When my grandmother needed help, the most common form of care for people who needed mental health treatment was placement in an asylum. More than half a million Americans with mental illness were in institutions during my father's childhood. The American Medical Association did not define alcoholism as a medical condition until 1952, and it would be four more years before it took the position that it is a "treatable disease, not a moral failing." The health insurance industry refused to pay for alcohol use disorder treatment until 1964. Even if she knew how to find them, my grandmother might have been the only woman in Alcoholics Anonymous (AA) meetings. (More than seventy years later, there still far more men than women who attend AA meetings).

My father was an adult before the tide would shift toward a system that may have provided better care for his mother. One of John F. Kennedy's final acts was signing into law the Community Mental Health Act of 1963, a "new approach to mental illness" that was based on the "open warmth of community concern and capability." The Act funded local services that would provide better care for families and their loved ones. JFK's plan was inspired by the experiences of his younger sister Rosemary, who had suffered greatly as a result of experimental treatments for her mental illness, and lived in an institution her entire adult life.

Our loved ones who are impacted by mental illness and substance use disorders today have more options. Effective medicines and community based treatment services have been developed. Unfortunately, not everyone can get them, and the average time between the beginning of mental health symptoms and getting treatment is eleven years. Services are limited by where people live, how they pay for care, their race and income, and the social stigma of getting help. American jails are full of people who have mental illness.

There are also signs of hope. National movements are celebrating long-term recovery from mental illness. People who are living in recovery from substance use disorders are sharing their stories and encouraging other people to do the same. Maybe the biggest difference from my grandmother's time is a new understanding: a 2015 survey of Americans found that 90% valued mental health equally with physical health. As more people understand and value mental health, maybe we will come closer to reaching the vision of community concern, and health care capability.

Post 4: Crowdsourcing Healthcare

When my husband and I moved to a new town with our young children in the mid-1990's, one of the first people I met was another mom. Our kids were the same age, and we became fast friends. She was a newly single mom with a good job and a mountain of medical debt. A few years before we met, she ate a kiwi fruit for the first time, and had a severe allergic reaction. She lost consciousness and was rushed to the hospital. Complications included plummeting blood pressure and dangerous heart rates. Her reaction was so severe that it took the doctors several days to stabilize her condition. Uninsured by her employer, she left the hospital with significant debt, no family in a position to help, and a commitment to monthly payments for many years to come. Several years into our friendship, she was still paying every month, and had taken on a second job to make ends meet.

Fast forward to late 2020. My extended family member had a medical event and was hospitalized during the holiday season. While conducting emergency surgery, his doctors identified more complications and scheduled a second surgery a few days later that resolved the problem. He had insurance through his employer with a high deductible that would be a financial stretch. Then he learned that the timing of his week-long hospital stay, which crossed from one calendar year into the next, meant he would have to pay the annual deductible twice. There was an outpouring of support as this news was shared. His coworkers set up a GoFundMe account, and family and friends from around the country made donations to help him pay his bill.

Crowdsourcing to pay medical expenses, an option that was not available to my friend over 25 years ago, has become common in America. GoFundMe has a full page devoted to medical fundraising on their site that reports over 250,000 medical fundraisers a year. A recent study of GoFundMe found 42 fundraisers for medical conditions in 2010, and over 119,000 by 2018. Collectively, these campaigns have raised more than $3 billion.

This level of support from friends and strangers on crowdsourcing platforms is not surprising. Sickness and injury are times when most people agree that communities should rally around individuals. Almost all developed countries have health care that is built around this shared value. Countries provide universal care in different ways, through a mix of national insurance plans and health services, but the central value is the same: health care is a basic human right. In contrast, the American health care system is not built on the value of helping anyone who falls sick, but on principles of competition and profit. This is no accident.

Americans started talking about universal health care at the same time as other western countries. Powerful political organizations including the American Medical Association have run successful campaigns against such a system for over seventy years. In 2021, four of the top ten spenders on lobbying were medical and pharmaceutical organizations. These high-powered campaigns have been successful for generations. But American public opinion has been changing as treatment has become less affordable even for people who have insurance.

Compared to other wealthy countries, America consistently spends more on health care and has worse outcomes. A 2021 Gallup poll found that 77% of Americans were dissatisfied with the total cost of care. Only 56% said it was the responsibility of the Federal government to make sure everyone is covered. This is a place where America is different from other countries: its citizens have never sent a unified message to the government that universal care is expected.

Changing America’s health care system to work better for the people it serves will not be easy, but it is possible. The first step may be naming the shared value we practice every time we hit the donate button: sickness and injury are times when everyone deserves to get the treatment they need.

Appendix D

Table 6. Survey Respondent Race or Ethnicity

Answer Choices	Responses	
Asian	13.55%	29
Black or African American	6.54%	14
Hispanic or Latino	7.94%	17
Middle Eastern or North African	1.87%	4
Multiracial or Multiethnic	4.67%	10
Native American or Alaska Native	0.93%	2
Native Hawaiian or other Pacific Islander	0.00%	0
White	62.15%	133
Prefer not to answer	1.87%	4
Another race or ethnicity, please describe below	0.47%	1
Comment:		5
	Answered	**214**
	Skipped	**0**

Table 7. Survey Respondent Age

Answer Choices	Responses	
18 to 24	14.95%	32
25 to 34	17.76%	38
35 to 44	19.63%	42
45 to 54	17.29%	37
55 to 64	14.49%	31
65 to 74	11.68%	25
75 or older	4.21%	9
	Answered	**214**
	Skipped	**0**

Table 8. Survey Respondent Gender

Answer Choices	Responses	
Female	48.60%	104
Male	49.07%	105
Prefer not to answer	0.93%	2
Another answer, please describe below	1.40%	3
Comment:		5
	Answered	**214**
	Skipped	**0**

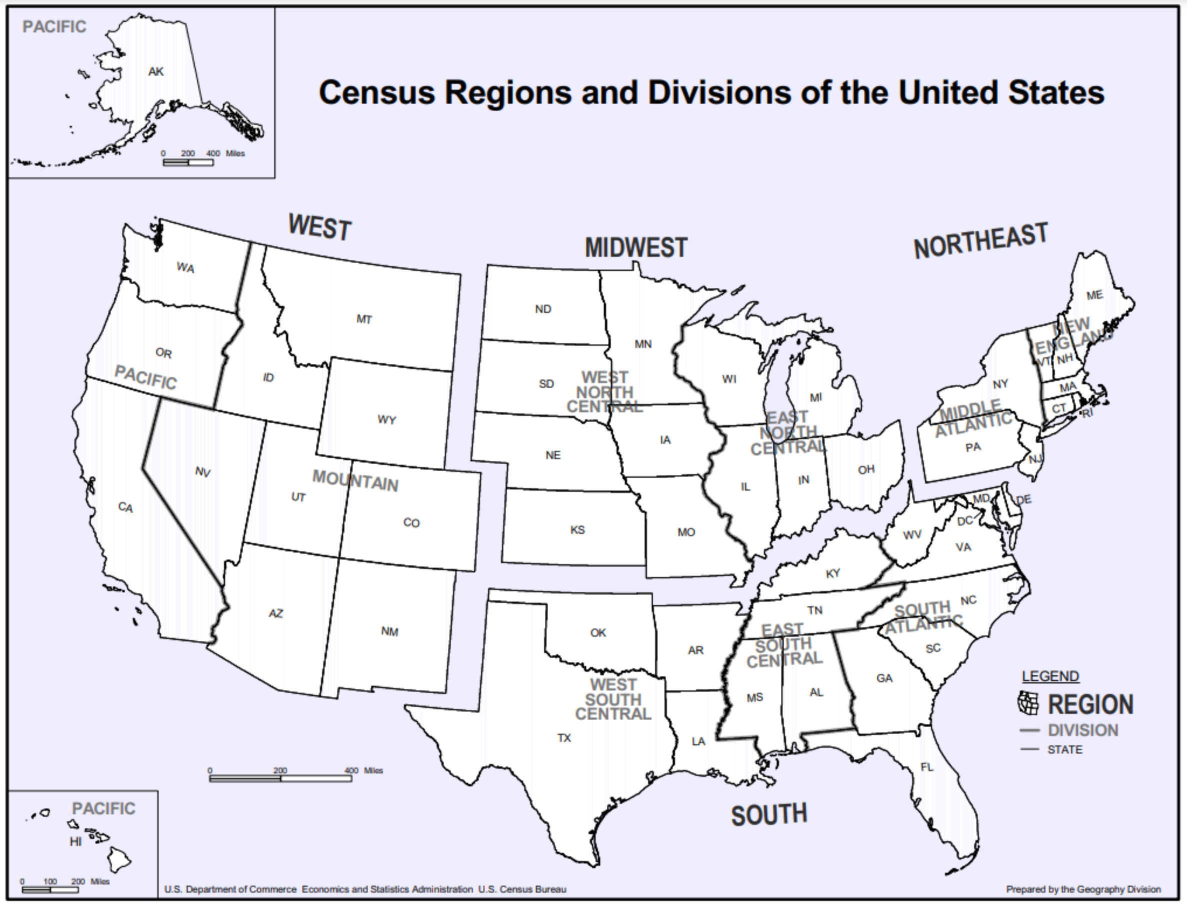
Table 9. Survey Respondent State of Residence

Answer Choices	# Responses	
Alabama	1.87%	4
Alaska	1.87%	4
Arizona	3.74%	8
Arkansas	0.00%	0
California	12.15%	26
Colorado	1.40%	3
Connecticut	2.34%	5
Delaware	0.47%	1
Washington	0.47%	1
Florida	6.07%	13
Georgia	2.34%	5
Hawaii	0.00%	0
Idaho	0.00%	0
Illinois	3.27%	7
Indiana	2.80%	6
Iowa	0.00%	0
Kansas	2.80%	6
Kentucky	1.87%	4
Louisiana	1.40%	3
Maine	0.47%	1
Maryland	1.87%	4
Massachusetts	0.47%	1
Michigan	1.87%	4
Minnesota	1.40%	3
Mississippi	0.47%	1
Missouri	0.93%	2
Montana	0.00%	0
Nebraska	0.93%	2
Nevada	0.47%	1
New Hampshire	0.00%	0
New Jersey	2.80%	6
New Mexico	2.34%	5
New York	5.14%	11
North Carolina	3.74%	8
North Dakota	0.00%	0
Ohio	3.74%	8
Oklahoma	0.00%	0
Oregon	1.40%	3
Pennsylvania	5.61%	12
Rhode Island	0.47%	1

South Carolina	0.93%	2
South Dakota	0.00%	0
Tennessee	1.87%	4
Texas	6.54%	14
Utah	0.47%	1
Vermont	0.00%	0
Virginia	2.80%	6
Washington	2.80%	6
West Virginia	1.40%	3
Wisconsin	4.21%	9
Wyoming	0.00%	0
	Answered	**214**

Appendix E

Figure 5. Census Regions and Divisions of the US (US Census Bureau, n.d.)



Appendix F

Data set with full survey results is available here.

Survey Monkey Audience

150 Completed Surveys Random U.S. Sample (paid service returned 214 surveys)

U.S. All Regions; Gender Both- Balancing Census; Age 18-99- Balancing Basic Census; Income 0-200k+

Survey Content:

Survey Page 1: In the Well: Healthcare Blog Feedback Survey

Thank you for completing this anonymous survey. All of your information and opinions will be kept confidential. This survey has 15 questions. This first page will collect some basic information. Then you will be asked to read or listen to some short social media posts and share your feedback. At the end, you will be asked to answer three final questions and have the option to provide comments. Your feedback will be used to improve future posts.

1. What state do you reside in?

- ○ Dropdown of states

2. What is your age?

- ○ 18 to 24
- ○ 25 to 34
- ○ 35 to 44
- ○ 45 to 54
- ○ 55 to 64
- ○ 65 to 74
- ○ 75 or older

3. What is your race or ethnicity?

- ○ Asian
- ○ Black or African American
- ○ Hispanic or Latino
- ○ Middle Eastern or North African
- ○ Multiracial or Multiethnic
- ○ Native American or Alaska Native
- ○ Native Hawaiian or other Pacific Islander
- ○ White
- ○ Prefer not to answer
- ○ Another race or ethnicity, please describe below

4. What is your gender?

- ○ Female
- ○ Male

- Prefer not to answer
- Another answer, please describe below

Survey Page 2

Please read this short blog post before answering the questions. If you prefer to listen to the post or read it on the blog site, you can paste this into a new page. *https://inthewell2022.blogspot.com/2022/02/the-broad-street-pump.html*

Blog post content (3,500 characters or less).

5. This post was interesting and made me want to read more.

- Extremely interested
- Very interested
- Somewhat interested
- Not so interested
- Not at all interested

6. I learned something new from this post.

- A great deal
- A lot
- A moderate amount
- A little
- None at all

Survey Page 3

Please read this short blog post before answering the questions. If you prefer to listen to the post or read it on the blog site, you can paste this into a new page. *https://inthewell2022.blogspot.com/2022/02/disability-generation-of-change.html*

Blog post content (3,500 characters or less).

7. The stories in this post were familiar to my own life experiences.

- Extremely familiar
- Very familiar
- Somewhat familiar
- Not so familiar
- Not at all familiar

8. I learned something new from this post.

- A great deal
- A lot
- A moderate amount
- A little
- None at all

Survey Page 4

Please read this short blog post before answering the questions. If you prefer to listen to the post or read it on the blog site, you can paste this into a new page.
https://inthewell2022.blogspot.com/2022/03/not-moral-failing.html

Blog post content (3,500 characters or less).

9. The stories in this post were familiar to my own life experiences.

- ○ Extremely familiar
- ○ Very familiar
- ○ Somewhat familiar
- ○ Not so familiar
- ○ Not at all familiar

10. I learned something new from this post.

- ○ A great deal
- ○ A lot
- ○ A moderate amount
- ○ A little
- ○ None at all

Survey Page 5

Please read this short blog post before answering the questions. If you prefer to listen to the post or read it on the blog site, you can paste this into a new page.
https://inthewell2022.blogspot.com/2022/03/crowdsourcing-healthcare.html

Blog post content (3,500 characters or less).

11. The stories in this post were familiar to my own life experiences.

- ○ Extremely familiar
- ○ Very familiar
- ○ Somewhat familiar
- ○ Not so familiar
- ○ Not at all familiar

12. I learned something new from this post.

- ○ A great deal
- ○ A lot
- ○ A moderate amount
- ○ A little
- ○ None at all

Survey Page 6

Please answer these final questions. Thank you for sharing your feedback!

13. After reading or listening to these posts, how much of an influence do you think public opinion has on our healthcare system?

- A great deal
- A lot
- A moderate amount
- A little
- None at all

14. Would you share these posts with other people?

- Definitely would
- Probably would
- Probably would not
- Definitely would not

15. Optional: Please share your views about the blog posts you just read. You may share anything that you feel is important.

References

Berwick, Donald M. (2009). What 'Patient-Centered' Should Mean: Confessions Of An Extremist. Health Affairs 28, no.4 (2009):w555-w565 doi: 10.1377/hlthaff.28.4.w555 originally published online May 19, 2009.

Bou-Karroum, L., El-Jardali, F., Hemadi, N., Faraj, Y., Ojha, U., Shahrour, M., Darzi, A., Ali, M., Doumit, C., Langlois, E. V., Melki, J., AbouHaidar, G. H., & Akl, E. A. (2017). Using media to impact health policy-making: an integrative systematic review. Implementation science : IS, 12(1), 52. https://doi.org/10.1186/s13012-017-0581-0 https://pubmed.ncbi.nlm.nih.gov/28420401/

Brega AG, Barnard J, Mabachi NM, Weiss BD, DeWalt DA, Brach C, Cifuentes M, Albright K, West, DR. (2015). AHRQ Health Literacy Universal Precautions Toolkit, Second Edition. (Prepared by Colorado Health Outcomes Program, University of Colorado Anschutz Medical Campus under Contract No. HHSA290200710008, TO#10.) AHRQ Publication No. 15-0023-EF. Rockville, MD. Agency for Healthcare Research and Quality. January 2015.

Hyber, Catherine (2021). Cybernews. https://cybernews.com/best-website-builders/blogger-review/

Institute for Healthcare Advancement (n.d.). Health Literacy Research and Practice. Retrieved 12.1.2021 from https://www.healthliteracysolutions.org/learning-lab/journal

Jones, B. (2020). Increasing share of Americans favor a single government program to provide health care coverage. Pew Research Center. September 29, 2020. https://pewrsr.ch/2SbPw2e

Kaiser Family Foundation (2020). Public Opinion on Single Payer, National Health Plans, and Expanding Access to Medicare Coverage. Kaiser Family Foundation Charts and Slides. Retrieved December 10, 2021, from https://www.kff.org/slideshow/public-opinion-on-single-payer-national-health-plans-and-expanding-access-to-medicare-coverage/

Osborne, Helen (2018). Health Literacy from A to Z: Practical Ways to Communicate Your Health Message. Second Edition. Aviva Publishing, NY. 2018.

Ratzan SC, Parker RM. (2000). Introduction. In , Selden C. R., Zorn M., Ratzan S. C., Parker R. M. (Eds.). National Library of Medicine Current Bibliographies in Medicine: Health Literacy. National Institutes of Health, U.S. Department of Health and Human Services.

Sandro Galea, MD, DrPH and Roger D. Vaughan, DrPH, MS (2018). The Public Conversation and the Public's Health: A Public Health of Consequence. American Journal of Public Health. December 2018 Am J Public Health. 2018 December; 108(12): 1590–1591. Published online 2018 December. doi: 10.2105/AJPH.2018.304780
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6236757/

Stone, Deborah (2013). Policy Paradox: The Art of Political Decision Making. Third Edition. W.W. Norton & Company. New York 2013.

SurveyMonkey (n.d.). https://www.surveymonkey.com/mp/find-survey-participants/

U.S. Centers for Disease Control and Prevention. (n.d.). CDC Policy Analysis. U.S. CDC Office of the Associate Director for Policy and Strategy. Retrieved May 12, 2021, from https://www.cdc.gov/policy/analysis/process/index.html