



Oral Health

Engaging in Story-Based Work: What Oral Health Organizations Need to Know

Organizations that interact with people with oral health needs are well-positioned to help identify and elevate stories that demonstrate the need for changes to our oral health system.

Advocates, activists, and professionals working in the field know that oral health is one of the greatest unmet health care needs in the United States. Unfortunately, public discussion of oral health problems often points toward personal responsibility, rather than systemic barriers and policy solutions, thus hampering oral health reform efforts.

We know from other issue-advocacy campaigns that *individual stories* are a uniquely powerful tool in awareness raising and change efforts. However, because of shame and lingering stereotypes, storytelling for oral health runs the risk of further cementing harmful stigmas, rather than fostering empathy or driving social change. Thanks to insights gained from recent research, we know that this doesn't necessarily need to be the case. Through careful planning and framing, it is possible to engage in storytelling efforts that drive conversation forward and humanize unmet oral health needs.

Many organizations are in the initial stages of raising awareness of oral health issues to the national and state levels, which means that there is a significant opportunity to set the climate for effective storytelling at the onset.

This issue brief will walk through best practices and lessons learned from other issue advocacy campaigns around storytelling and apply those to recent messaging¹ and research efforts² around oral health issues.

Organizations that want to begin collecting stories as part of their advocacy around oral health work need to understand:

- » The basics of story collection
- » Ethical story collection and sharing
- » Developing and disseminating stories in ways that break stigmas about oral health, rather than further them

The Basics of Story Collection

Whether an organization has a long history of featuring personal stories or is new to the practice, it is important for the organization to think through its storytelling program. Collecting and highlighting stories requires thoughtful planning and an emphasis on empowering individuals.

Organizations must also be both ethical and responsible when it comes to collecting and disseminating stories.

Creating a Story Bank

Many organizations that choose to collect stories house them in a centralized location called a *story bank*. Often, organizations will use a database or spreadsheet system to store contact information and notes on storytellers

(anyone who has agreed to share his or her story), rather than relying on individual staff members to keep track of stories. A centralized, easily accessible story bank can come in handy when a member of the media expresses an interest in talking to a “real person,” or when the organization wants to incorporate stories into its activities.

Building a story bank is a three-step process:

1. Identifying people who are willing to share their stories
2. Developing stories (getting a full picture and verifying details)
3. Disseminating stories publicly

Below, we provide a brief overview of these three steps. An organization may choose to handle all three steps itself, or it may choose to partner with a third-party organization to accomplish some of this work.

For more comprehensive information about how to create a story bank program, see our Story Bank Toolkit (<http://familiesusa.org/story-banktoolkit>) and our brief, *How to Create a Successful Story Banking Program* (<http://familiesusa.org/product/how-create-successful-story-bank-program>). While these materials are geared toward an audience that works on issues related to the Affordable Care Act, the principles discussed in each can be easily modified for any subject.

Organizations need to remember that, before they share stories publicly or connect consumers to story sharing opportunities, they should dedicate time to vetting and fact-checking stories. This process, while sometimes time-consuming, ensures that stories that are publicly disseminated are true and accurate, which can save both the organizations and their storytellers from potential embarrassment.

1) Identifying People Who Are Willing to Share Their Stories

One of the easiest ways for organizations to create a story bank is to begin by identifying people who are willing to share their stories. If an organization wants to collect stories on a specific topic, it should “go to where the people are.” Thus, for a story bank focused on topics related to oral health, the organization should figure out how to integrate story collection into places when and where the organization interacts with individuals who have oral health needs.

Collecting stories can happen in two ways:

- » Through digital collection methods: for example, a web form, an email campaign, or social media
- » At in-person activities: for example, during face-to-face interactions such as an appointment, meeting, conversation at an event, or phone call

Partnering

If your organization is interested in partnering with Families USA on any efforts, please send a note to storybank@familiesusa.org.

Any information that is collected or submitted, including contact information and a brief description of the story (called a “story lead” or “lead”), can then serve as the basis for interactions between the organization, the individual, and any other parties.

Please note: if an organization is subject to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) or handles Personally Identifiable Information (PII), it may need to take additional steps to secure individuals’ consent and meet its legal obligations to patient privacy.

2) Developing Stories

Before sharing a story publicly, an organization must “develop” the story. That means gathering a complete picture of the circumstances of the experience the storyteller is sharing with an organization. This is done through conducting a more in-depth interview to flesh out elements of the story, verify information, and check details in the story against publicly available information.

For stories that involve eligibility for particular benefits or programs, it is especially important to clarify which program an individual is eligible for, the specifics of that person’s benefits, and whether they have experienced any trouble with that particular program.

Storytellers, especially those with low health literacy, may unknowingly misrepresent parts of their story. For example, an individual who lives in a state where Medicaid only covers preventive dental services and

who needs dentures, may say that they don’t have any dental benefits because the service *they* need is not accessible. Therefore, it’s not factually accurate to say that the individual has no dental benefits; actually, the situation is more complicated than that.

Storytellers need not be policy experts to speak publicly, but organizations who help individuals share their stories can help tease out related details and policy facts to ensure it is framed accurately.

Developing a story allows an organization to ensure that any story it shares is accurate and based on facts. An interview can also highlight relevant aspects of an individual’s experience and help bring clarity to the story.

3) Disseminating Stories Publicly

As soon as an organization starts to develop stories, it can begin incorporating the voices of storytellers in its work. There are countless ways that personal stories can strengthen an organization’s activities, from public communications to outreach. The following includes some of the ways organizations can disseminate stories:

- » Working with the media
- » Creating testimonials or short videos
- » Incorporating stories into advocacy, public education, and outreach materials
- » Asking storytellers to share their stories at in-person events, such as town hall meetings or outreach events

Organizations should think creatively about how they want to engage in storytelling throughout their in-reach (which involves current clients, patients, or supporters), outreach (which involves new clients, patients, or supporters), and public education efforts.

Whether storytellers publicly share their stories themselves or an organization shares their stories on their behalf, organizations should talk to storytellers before each story sharing opportunity, so that storytellers know how, when, and where their stories will be highlighted.

Ethical Story Collecting and Sharing

If an organization chooses to engage in story collection and story sharing, it must take every precaution to ensure that it engages in these activities ethically. This means ensuring that stories are factually accurate and based on true accounts, and that storytellers are active, willing participants in the public dissemination of their stories. It can be tempting to share stories from which identifying characteristics have been removed (such as a storyteller's name) or through creating composites. However, to engage in ethical storytelling, it is necessary to stay grounded in accurate, verifiable stories about real people.

Furthermore, storytellers should always remain the owners of their stories. They must always give their permission before their story, likeness, or contact information is shared, even if they have already shared their experience with an organization. Organizations must develop protocols to support storytellers from the

point of collection all the way through public storytelling opportunities and beyond. Publicly sharing a story can be a daunting prospect for some individuals. It's important for organizations to show storytellers that they are not alone in any opportunity, and to make sure that they are comfortable throughout the process.

Organizations can do this by:

- » Working with storytellers before any storytelling opportunity to provide guidance and tips
- » Always securing consent before sharing stories or connecting someone to an opportunity including always providing the ability to “opt-out” of participation
- » Being up-front about where, when, and how the organization will disseminate their stories

Developing and Disseminating Stories to Break Stigma

The two primary areas where organizations have an opportunity to engage in impactful storytelling are during the story development and dissemination phases. Through careful, mindful planning, it is possible to lay the groundwork for changing public perception of oral health issues.

On the other hand, individual stories can also present a challenge in oral health advocacy. The reason is that there is a danger that any one individual's story could further the belief that oral health problems are generally

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caused by a lack of personal responsibility, rather than by structural or systemic problems.

Therefore, it is critical to think through the “locks and doors”³ that can exist in an individual’s oral health care. Utilizing this metaphor in story development and dissemination is critical to ensuring the focus is on structural and systemic problems, rather than an individual’s actions (or inaction).

Take the following story from Pat as an example:

I have four severely decayed teeth and I think that I might need oral surgery. I haven’t been to the dentist in a number of years and don’t know how much it would cost to fix my teeth—probably thousands of dollars.

As it is currently framed, the story’s emphasis is on Pat and her teeth. While Pat’s situation is sympathetic to oral health advocates, the current framing may lead a reader to assume that Pat is the cause of her own oral health problems. There is no discussion of the structural or systemic barriers that Pat may face. Accordingly, the current framing offers no solutions and furthers the belief that nothing can be done to solve for oral health problems beyond encouraging people to take better care of themselves.

To better understand Pat’s situation, an organization that wishes to help her share her story publicly, or include her situation in their materials, needs to do three things: 1) develop the story through an interview to better understand the “locks and doors” that Pat

faces in receiving oral health care, 2) make every effort to include those details in any dissemination opportunity; and 3) link Pat’s story to actionable solutions or “keys” to show that change is possible.

Developing Stories

To develop stories through interviews, it is beneficial to have a “master list” of questions and topics to explore during interactions with storytellers. For the purposes of this conversation, we are going to call this document a *vetting script*.

Organizations should create a vetting script at the outset of each new project. Doing so will help during educational background research, in conversations around messaging, and in thinking through potential story themes.

For the purposes of developing a vetting script related to oral health, look to develop questions based on the barriers or doors that individuals face, as well as the potential solutions, or keys, to those problems.

Every organization will necessarily have a unique script, because there will be differences in priorities and emphases. For example, one organization may work exclusively on a dental benefit in Medicare, while another may work on pediatric issues. Organizations should tailor their scripts to their individual needs.

As an example, the following list is a series of questions that could be asked about dental insurance:

Do you currently have dental insurance?

(If yes)

How do you receive your dental insurance? (Through an employer, through the marketplace, through Medicaid, etc.)

Who is covered through your dental insurance? (Just you, or you and family members?)

Is your coverage affordable? (How much do you pay? For you? For your family members?) How does your coverage help with the cost of receiving care?

Do you find that your coverage meets your needs? Why or why not?

Have you ever found that your coverage is insufficient? How so?

If you could make any change to your coverage, what would it be?

(If no)

You don't have dental insurance, what prevents you from getting it? (Cost, lack of access, etc.)

How has not having dental insurance impacted your ability to receive care?

If you were to have a dental emergency, what would you do?

Here, the door that is explored is insurance. The questions are designed to probe the kind of coverage the individual has, how they access their coverage, the structure of the plan, its adequacy, and whether their oral health needs are met. By covering this array of topics, the interviewer creates an opening for potentially rich anecdotes and details. The same kind of exercise can be utilized to explore other avenues, including access to providers, availability of services, design of oral health benefits, impact of oral health needs on other health issues, etc.

As an organization develops questions, it also make sure to look to the values that it wants to highlight in their work. Many of the effective values listed in the FrameWorks messaging research⁴ can be teased out through the conversation. Depending on how questions are framed and the storyteller's responses, it is possible to tease out elements of prevention, responsible management of resources, and more.

Let's turn back to Pat:

In an interview with Pat, the interviewer explores questions about Pat's dental insurance status, her overall health, and the problems she faces in accessing care. During their conversation, it becomes clear that Pat is on a medication that has a side effect of a dry mouth. Despite brushing regularly, she has developed severe tooth decay. Pat indicates that while she used to receive dental insurance through her work and went for cleanings, she

stopped being able to afford preventive services when she transitioned onto Medicare and dental care was no longer covered. Without insurance, she is unable to afford out-of-pocket costs for care and has avoided going to the dentist. Thus, the main barriers to her care are two-fold: cost and lack of dental coverage.

Here, Pat's responses not only shed light on her situation, but they also demonstrate that her story speaks to the values of prevention and responsible management: her situation could be avoided, if only a benefit and preventive services were available.

Disseminating Stories

There are a wide variety of ways that organizations can choose to disseminate stories, and this can be one of the most creative, fulfilling parts of story-based work.

Media

There are two basic forms of media: earned and owned media. Each of these presents a slightly different set of challenges to framing an oral health story, as the degree of influence that an organization has in these opportunities varies.

Owned Media. Owned media channels are any platforms that an organization owns. This includes organizational websites, blogs, brochures, promotional materials, and social media channels. Since this is content created by an organization for their use, they

may have a great amount of leeway in ensuring that stories are framed appropriately. Staff should work with individuals crafting language to ensure that both the nuances of the story and the framing are included in every dissemination opportunity.

For example, a social media post around Pat's story might look like this:

Pat is one of millions of seniors who are unable to afford dental care without insurance. Our new blog explains why dental benefits are a critical and missing part of Medicare. [link to blog]

Earned Media. Earned media is media that is neither owned by the organization nor paid for. This is content that is generated by others outside of an organization—including individuals such as journalists, people who communicate on social media, and through word of mouth.

Because of the nature of earned media, effective framing is trickier: there's no guarantee of what will happen. Even so, earned media presents an unparalleled opportunity. If a staff member is working with journalists to either pitch stories or fill requests, there are two ways to combat this. 1) Consider offering an expert in the organization who can help provide background, and 2) work with the storyteller in advance through coaching so that when they tell their story, they can make sure to highlight the barriers they faced to receiving care.

Here is how a media opportunity for Pat might proceed:

Your organization wants to highlight that the lack of a Medicare dental benefit is a problem faced by many senior citizens. You work with the individual in charge of media in your organization to provide a policy expert to provide needed context about the problem, and you identify that Pat is a good fit. When you ask Pat to share her story with a reporter, you explain to her that the story will focus on Medicare's not having a dental benefit. You also encourage her to speak about the burden that lack of oral health coverage has placed on her ability to receive oral health care, since she cannot afford dental services without insurance.

Advocacy

It is a good rule of thumb to always link back to the cause of the problem and the solution. It can be tempting to spend time in speeches, remarks, and testimony focusing on the problems that are at hand. But in order to be most impactful, it is critical to spend time talking about the solutions to the structural and systemic problems. Otherwise, the problems will continue to seem related to an individual's actions or like an insurmountable task.

Again, we turn to Pat as an example.

At an event, Pat has two minutes to share her story publicly. To make the best use of her time, Pat addresses her problem and then pivots to the solution: a dental benefit in Medicare.

My name is Pat and I am a 70-year-old woman from Chicago. I've been fortunate that for most of my life, I have been extremely healthy, so I've rarely had to go to the doctor. And I've always taken good care of my teeth.

About ten years ago, my doctor noticed that I had a bit of high blood pressure and he put me on a new medication. Unfortunately, one of the biggest side effects of that medication is dry mouth. For the first couple of years on the medication, I was still working, so I got dental insurance through my employer. I scheduled cleanings a couple of times a year and everything was OK. Unfortunately, when I retired, I went onto Medicare, which doesn't cover dental services. So even though I take care of my teeth the same way I always have, my teeth started decaying because going to the dentist was too expensive.

Now, my molars are rotting and I'm in constant pain. There are nights I wake up, feeling my jaw throb in pain. So I get up, take a thousand milligrams of ibuprofen, and try to go back to sleep. But most of the time I stay awake and pray that the pain will go away.

It's been five years since I've been to the dentist and to be honest, I'm too afraid to go now. I know it's going to be expensive because Medicare doesn't cover any dental treatments. What could have been a simple, relatively inexpensive problem to fix if it had been covered by insurance, is now a huge

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problem and it will cost a lot of money—money that frankly, I don't have.

This is why we need a dental benefit in Medicare. Right now, millions of seniors like me are forced to pay out of pocket for anything that comes up. And since many of us are on a limited income, it's especially difficult. In my mind, I keep coming back to the fact that this could have been avoided, if only preventive services were covered in Medicare. I know if I were to have access to dental treatment, I would be able to sleep through the night again. I can't tell you how much that would mean to me.

Now, Pat's story includes details from her initial story submission, plus information gathered in the interview, a link to values, and a clear explanation of the “locks and keys” that would allow her to achieve oral health. Through this framing, Pat's story becomes representative of millions of other individuals who face similar problems and, just as importantly, the solution to these problems. It becomes less about Pat herself—but at the same time, it becomes more focused and persuasive.

While this example pretends that Pat is the main speaker, the same principles would apply if someone were sharing Pat's story on her behalf.

Stories help illustrate an important narrative, address misinformation, and rally support around a campaign, public program, or law.

While story-based work requires a substantial investment in organizational time and energy, it is an invaluable tactic for organizations, and can be extremely rewarding for storytellers.

It is our hope that these tips and strategies will provide organizations with the information they need to think through how to integrate oral health stories in their efforts to ensure everyone has access to oral health care.

Endnotes

¹Patrick Willard/Families USA, *Public Supports Better Insurance Coverage for Dental Care, Survey Finds* (Washington, DC: Families USA, December 14, 2017), available online at <http://familiesusa.org/blog/2017/12/public-supports-better-insurance-coverage-dental-care-survey-finds>.

²Frameworks Institute, *Reframing Oral Health* (Frameworks Institute, undated), available online at <http://www.frameworksinstitute.org/toolkits/dentaquest/>.

³Frameworks Institute, *Recommendation #4: Use the Keys to Oral Health metaphor to explain systemic barriers* (Frameworks Institute, undated), available online at <http://www.frameworksinstitute.org/toolkits/dentaquest/fr4.html>.

⁴Frameworks Institute, *Keys to Oral Health* (Frameworks Institute, undated), available online at http://www.frameworksinstitute.org/toolkits/dentaquest/assets/pdf/oral_health_reframe_cards.pdf.

A selected list of relevant publications to date:

Collecting Consumers' Health Care Stories: What Enrollment Assistance Organizations Need to Know (February 2016)

Story Bank Toolkit (February 2016)

How to Create a Successful Story Banking Program (January 2015)

For a more current list, visit:

familiesusa.org/publications

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