Promoting Vaccine Confidence in Neurodivergent Communities

*Lessons Learned from Stakeholder Engagement and Social Media Outreach*

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INTRODUCTION
Overview

Project Aim
To promote vaccine confidence in the disability community

Approach
Student-driven stakeholder interviews and social media to disseminate lessons learned

Collaborations
AUCD, CDC, UCLA, UC-LEND, Hood Medicine, LA COVID Volunteers

Our Overall Mission
Promoting health and well-being for neurodivergent communities

In one study, over 25% of disabled individuals expressed vaccine hesitancy
Accomplishments

Stakeholder Engagement
• Interviewed self-advocates, family members, DSPs, & experts in English & Spanish
• Created a blog series & a report of barriers, facilitators, & recommendations.

Social Media and Outreach
• Informed by stakeholder engagement & Hood Medicine
• Developed infographics & tailored messaging across platforms

Infrastructure Building
• Neurodiversity Health Chats
LESSONS LEARNED FROM SELF-ADVOCATE AND FAMILY MEMBERS
It is imperative to hear directly from the voices that are most impacted in the disability community. Hear a wide range of perspectives and voices. Learn how to most effectively reach out to the community.

**Why?**

**Self advocates:**
- Zina Jawadi
- Zach Williams

**Family members:**
- Dr. Jodi Coates
- Lynne
Meet the Self Advocates

Zina Jawadi
UCLA Medical Student and Advocate

Zachary Williams
Vanderbilt MD/PhD Student
Meet the Family Members

Dr. Jodi Coates
Critical Care Surgeon at Mercy San Juan Medical Center, Advocate for her daughter, “A” with Rett’s Syndrome

“...they should just keep it **positive** like this is why you should get it...you know don't tell me about the **negative** stuff because that makes us more scared...”

Lynne
Family Member and Advocate for her children

“...to me, it [COVID vaccine] was very reassuring that at some point she [“A”] will also be **protected** from something that could be significantly more dangerous for her than her siblings...”
More Lessons Learned

**SOCIAL NETWORKS**
Don’t shy away from talking to friends/family that are vaccine hesitant

**COMMUNITY BASED RESEARCH**
Partner with the people your research is going to affect

**RESEARCH**
Support the community in their research on vaccine related topics

**TRAINING**
Direct neurodiversity training for physicians/healthcare workers is necessary
Having a positive vaccine experience

Written by Asal Bastani

NDHC Incorporation

DIFFERENT PATIENTS HAVE DIFFERENT MEDICAL PREFERENCES!

...SOME PEOPLE REALLY ENJOY DETAILS ...
...SOME GET VERY OVERWHELMED WITH THAT DEGREE OF INFORMATION.
Next Steps

Community

● When explaining the pandemic and vaccine to your kids, use simple language and analogies, like “cooties”

● Actively research using reputable sources, and be aware/critical of the circles you are in if they are citing unreliable sources

Healthcare Professionals

● Support individuals in advocating for themselves; have accommodations readily available

● Highlight benefits and reasons to get the vaccines for patients

● Explain the potential side effects and why they occur, and use accessible language

● Use accessible language and build an environment where patients can share their needs and questions. “Be an open book”
03 LESSONS LEARNE FROM PUBLIC HEAL PROFESSIONALS
Lessons Learned from Public Health Professionals

Why is this important?

- Lessons learned from the COVID-19 pandemic will inform prevention, interventions, and policy to protect neurodivergent and other impacted populations.

- Important to dispel myths with accurate information that is accessible to all populations.
Lessons Learned: Barriers

**Disparities & Disproportionate Effects of COVID-19**
- Access to health & social services
- Health insurance
- Unequal distribution of resources
- Comorbidities

**Common Misconceptions about the COVID-19 Vaccine**
- Newness of vaccine
- Infertility
- Altering genetic makeup
- Vaccine containing coronavirus

**Access to Vaccination Sites**
- Proximity
- Accommodations
Lessons Learned: Improving Vaccination Efforts

Availability of Accessible Information

Public Health Messaging

Including Neurodiverse Voices

- Culturally Receptive
- Clear Communication
- Neurodiverse Friendly
- Simple Language
- Including images/examples
- Relatability
- Community involvement
- Educating the general public
“Individuals who are neurodiverse, have disabilities or have other at-risk factors can look to organizations that they closely work with in order to be better informed on how the vaccine may affect them specifically. There's a variety of associations for specific conditions, and they are there to support, especially because there are people who may be impacted by the vaccine in varied ways.”

“We have to consult with the disability community and really let the disability community guide the messaging for families and children to get the vaccine.”
LESSONS LEARNED FROM DIRECT SERVICE PROVIDERS
These voices are important to understand the most effective ways to communicate with patients regarding vaccine confidence and hesitancy.
Lessons Learned:

Barriers

1. Sensory sensitivities, needle phobias, or other anxieties

1. Mistrust in medical system based on historical injustices

1. Socio-economic barriers
“[Certain communities] are faced with a situation where they’re having to gain trust. And statement of medical rescue / medical health -- that’s quite a conundrum [for them].”

“Because the vaccination involves a needle that does puncture the skin and on top of the anxiety of neurosensory issues this population may have increased challenges with receiving a vaccination or getting blood drawn”  
(Physician)

“Mental health like depression will play a major role in how you interact with the medical system. Vaccines fall under this. Anxiety about losing a whole day of work or childcare could be time they cannot lose... Vaccines may not be at the highest level of needs. Stress related to survival may get in the way to adhere to public health recommendations.”  
(Social Worker)
Lessons Learned: Facilitators

1. Compassionate, open, non-judgemental, patience, honest, and reciprocal conversation with patients

1. Providing factual information

1. Meeting people at their level (e.g., understanding)
“A 14-year-old with a rare genetic condition had a completely pleasant experience, barely even notice that he had gotten the vaccine by the time was done, and left, with a smile on his face, not having that negative association. And that's gonna make our lives much easier next time if he needs a boost for vaccine.” (Physician)

“We don't ever want someone to feel that ‘you must have this vaccine.’ It's always their choice, but we want to empower them to understand to the best of our knowledge to really make a good, informed decision.” (Registered Nurse)

“If it is an older patient with a neurodevelopmental disability or something like that it really is meeting them where at the level … giving them a chance to answer any questions that they have, and get those concerns addressed.” (Physician)
Lessons Learned:

Recommendations

1. Develop communication strategies that help healthcare providers discuss vaccine hesitancy with their patients.

1. Making the vaccine more accessible to all communities (e.g., mobile vaccine centers, increase vaccine information accessibility).

1. Increase awareness of needle anxiety accommodations.
Spanish is Spoken Throughout Los Angeles

Nearly 45% of the LA metropolitan area speaks Spanish at home

Data Source: US Census
Visualization Credit: Data USA
Targeted outreach to the Latinx community is necessary to increase vaccination rates and reduce the disparity.

1. Spanish-speakers make up a significant proportion of the LA population.
2. Latinos are proportionally less vaccinated than other races in California.

Source: California State
Our Spanish Language Interviews

Dr. Maria Elena Bottazzi
Microbiologist

Bobby Verdugo, LCSW
Mental Health Specialist

Future outreach with public health departments with a Spanish-speaking focus
Lessons Learned: Barriers Faced by the Latinx Community

Barriers the Latinx community and with disabilities faces with regards to access:

○ Language, Immigration Status, distrust in the government and documentation
○ Access to computer and navigating online platform
○ Economic disenfranchisement: unstable employment (individuals may not be able to take time off to get vaccine or take days off as a result of the vaccine side effects).
○ Communication with all stakeholders in the individual's life is essential to building vaccine confidence
Lessons Learned: Vaccine Misconceptions In the Latinx Community

Common misconceptions in the Latinx with disability community:

1. The vaccine was developed too fast
   FACT: Vaccines against coronaviruses/using mRNA technology have been studied for over a decade

2. The vaccine has a tracking device
   FACT: The vaccine does not have a tracking device

3. The vaccine impacts reproductive health
   FACT: The vaccine elicits an immune response, and the contents are degraded within a few days

4. The vaccine alters DNA and RNA
   FACT: The vaccine does not alter the genome

5. The vaccine gives you the virus
   FACT: None of the vaccines currently in circulation contain the live SARS-CoV-2 virus
Lessons Learned: How Can We Support the Spanish-Speaking Community?

- Workplaces and Community Centers
- Targeted Community Support
- Non-Judgemental Conversations
LESSONS LEARNED ON INNOVATIVE WAYS TO DISSEMINATE PUBLIC HEALTH INFORMATION
PILLARS OF ONLINE WRITING

Creating digestible content
Boil down ideas so the average reader can understand complex topics.

Drawing Empathy
Talk about real stories and try to understand the same problem from multiple perspectives.

Taking a stance
Make sure readers take away something from your content.
Creating Digestible Content

- Use simple vocabulary
  - Define complex vocabulary
- Use short sentences
- Link to different sources in articles so readers can further educate themselves on the topic
Drawing Empathy

- Telling real stories
- Make your content relatable: People want to feel heard
- Give a voice to those who need it
Taking a stance

- What is the takeaway and why should people care?
- Research and make an educated opinion
- Get help from the experts (stakeholders)
Op-ed: COVID-19 vaccine hesitancy is a product of structural racism

“Public health decisions require the trust of constituents...To begin engendering trust, this nation must condemn violent crimes against the Black community, specifically those committed by the carceral state.”

Needle Anxiety Program: Lessons Learned from Program Leadership

By: Laila Riazi-Gani

Needle anxiety refers to a phobia of needles that impairs someone's ability to receive vaccines, injections, or other procedures that require needles. It's estimated that up to 10% of the general population suffers from some form of needle phobia. Additionally, it's expected that needle anxiety, in conjunction with other factors, may have contributed to low vaccination rates among the disability community during the pandemic. We at NDHC had the opportunity to interview diabetics and staff with UCLA's needle anxiety program to get a better understanding of what needle anxiety is and how it impacts the neurodiverse community.

Talking about Vaccine Hesitancy

By: Aziyadah

As more and more people become eligible to get the COVID-19 vaccine, not everyone is so thrilled at the thought of being vaccinated. People who are “on the fence” about vaccinations are what we call “vaccine hesitant.” This opinion piece discusses various techniques that one can take when talking about vaccines to someone who is vaccine hesitant.
Social Media Statistics

Instagram
- 117 followers
- 30 posts
- Highest engagement post: 27 likes
- Highest engagement video: 110 views

Twitter
- 78 followers
- 55 Tweets
- Highest engagement tweet: 52 likes and 29 reshares
Interview Posts

Statistics on needle anxiety in the general and disabled populations:

"If needle anxiety is contributing to people not getting the COVID-19 vaccine, I think we definitely want to address that."

To view the full interview, please visit our website (link in bio).
COVID-19 and the Disability Community

Individuals with disabilities are disproportionately affected by COVID-19.

Disability Pride Month

The COVID-19 pandemic negatively impacted the mental health of 93% of autistic adults.
Challenges With Social Media

- Focusing on topics relevant to our community
- Digesting statistics and information into a condensed format
  - Word count
- Familiarizing ourselves with image descriptions and alt text
- Consistency
  - Citation
- Visual Appeal
  - Colors
  - Text Size
- Growing our audience

Recommendations

During COVID-19:
- Maximizing the online format

Post COVID-19:
- Continuing to grow your audience
Website
Website Development Challenges

- **Increasing site traffic**
  - Solution: Linking website on social media platform using linktree which consolidates multiple links

- **Providing updated and reliable information and statistics on COVID-19**
  - Solution: Thoroughly research commonly asked questions and use multiple credible research papers to answer it. Link all the sources used.

- **Providing unique and valuable information to user**
  - Solution: Created “Perspectives” page where we compiled interviews from stakeholders, self-advocates, public health experts, and direct service providers.

- **User Interaction**
  - Solution: Created blog posts to regularly bring new content to the website. We have comment box which allows users to interact with blog posts.
Key Website Takeaways

Utilize Established Website
- Established credibility
- Important for fast-paced projects

Outline Goals
- Emphasize uniqueness
- Explain details of mission
- Convey vision for project

Connect
- Link to other social media platforms

Engagement
- Target content to audience
- Make website interactive
- Integrate forum
Stay in touch

Get in touch
@NDHealthChats on Instagram
Email: ehotez@mednet.ucla.edu

Watch our interviews
https://www.uc-lend.med.ucla.edu/perspectives/

Read our blogs & opeds
https://www.uc-lend.med.ucla.edu/blog-posts/

Learn more
Check out our content!

Thank you for listening!
Any questions?

Link:
https://linktr.ee/neurodiversityhealthchats