



Neurodiversity Health Chats



Promoting Vaccine Confidence in Neurodivergent Communities

Lessons Learned from Stakeholder Engagement and Social Media Outreach



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TABLE OF CONTENTS



ABOUT US
NEURODIVERSITY HEALTH
CHATS INCEPTION AND
PROJECT GOALS



LESSONS LEARNED
FROM SELF-ADVOCATES
AND FAMILY MEMBERS



LESSONS LEARNED
FROM PUBLIC HEALTH
PROFESSIONALS



LESSONS
LEARNED
FROM DIRECT
SERVICE
PROVIDERS



LATINX
FOCUSED
OUTREACH



DISSEMINATION
OF MATERIALS
FOR SOCIAL
MEDIA



QUESTION
AND ANSWER



01

INTRODUCTION



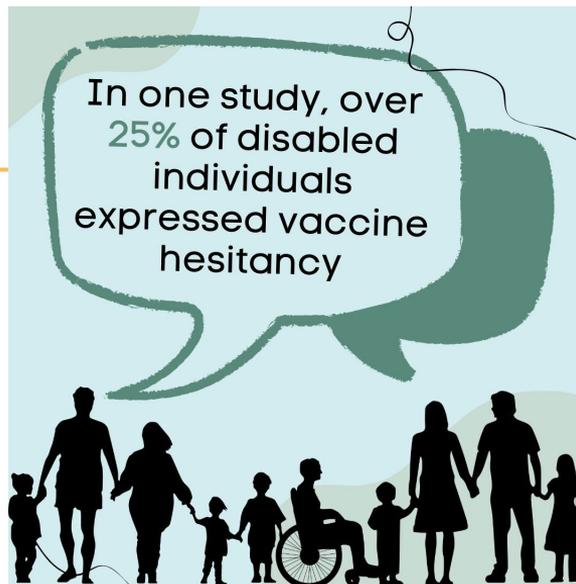
Overview

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



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



Entrevista en Instagram Live sobre la Vacuna COVID-19

CUANDO: 1:00 PM PST

CON QUIEN

DONDE:
@ndhealthchats IG LIVE

QUE: En esta entrevista, discutiremos las dudas sobre vacunas dentro de las comunidades Latinx y discapacitadas.



Dr. Maria Elena Botazzi

Profesora y Decana
Asociada en Baylor
College of Medicine



02

LESSONS LEARNED
FROM SELF-ADVOCATE
AND FAMILY MEMBERS



Why?

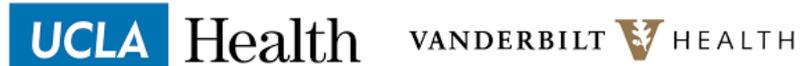
- It is imperative to hear directly from the voices that are **most impacted** in the disability community
- Hear a wide range of perspectives and voices
- Learn how to most effectively reach out to the community

Self advocates:

- Zina Jawadi
- Zach Williams

Family members:

- Dr. Jodi Coates
- Lynne





Meet the Self Advocates

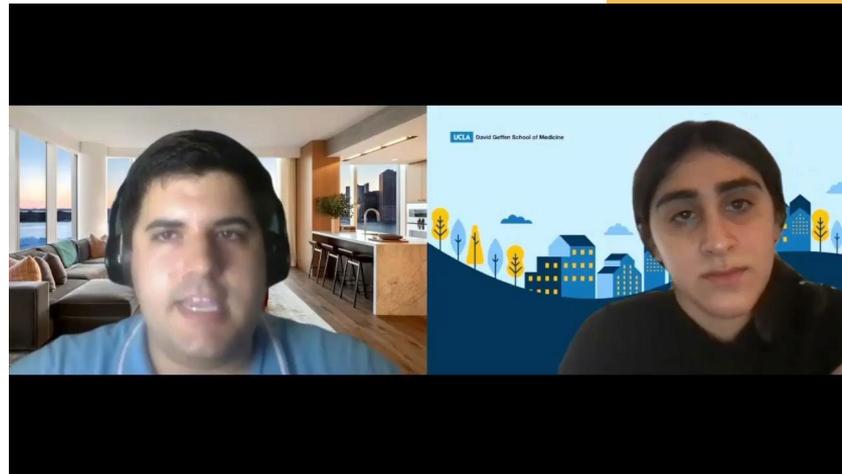
Zina Jawadi

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

“...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...”

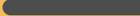
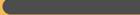
“...they should just keep it **positive** like this is why you should get it...you know don't tell me about the **negative** stuff because that makes us more scared...”

Lynne

Family Member and Advocate for her children



More Lessons Learned



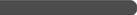
SOCIAL NETWORKS

Don't shy away from talking to friends/family that are vaccine hesitant



RESEARCH

Support the community in their research on vaccine related topics



COMMUNITY BASED RESEARCH

Partner with the people your research is going to affect



TRAINING

Direct neurodiversity training for physicians/healthcare workers is necessary





NDHC Incorporation

DIFFERENT
PATIENTS
HAVE DIFFERENT
MEDICAL
PREFERENCES!



"...**SOME** PEOPLE REALLY
ENJOY

DETAILS

...**SOME** GET VERY

OVERWHELMED

WITH THAT
DEGREE OF INFORMATION."



SUPPORT YOUR
FRIENDS AND
FAMILIES WITH
DISABILITIES



BLOG POST #3

Having a positive vaccine experience

Written by Asal Bastani





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 LEARNED
FROM PUBLIC HEALTH
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



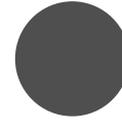
Disparities & Disproportionate Effects of COVID-19

- 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

- Culturally Receptive
- Clear Communication
- Neurodiverse Friendly



Public Health Messaging

- Neurodiverse Friendly
- Simple Language
- Including images/examples
- Relatability



Including Neurodiverse Voices

- Community involvement
- Educating the general public

Quotes

“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.”



04

LESSONS LEARNED FROM DIRECT SERVICE PROVIDERS

Hood Medicine

**Needle Anxiety
Program**

**Anxiety
Behavioral
Research
Program**

**Child & Adolescent
Psychiatrist, MD**

**Registered Nurse,
RN**

**Licensed Clinical
Social Worker,
LCSW**

**MS, PhD Retired
Psychologist, PhD,
MS**

Physicians, MD

These voices are important to understand the most effective ways to communicate with patients regarding vaccine confidence and hesitancy.

1. Sensory sensitivities, needle phobias, or other anxieties
1. Mistrust in medical system based on historical injustices
1. Socio-economic barriers

**Lessons
Learned:**

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)

“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)

“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)

“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)

Lessons Learned: Recommendations

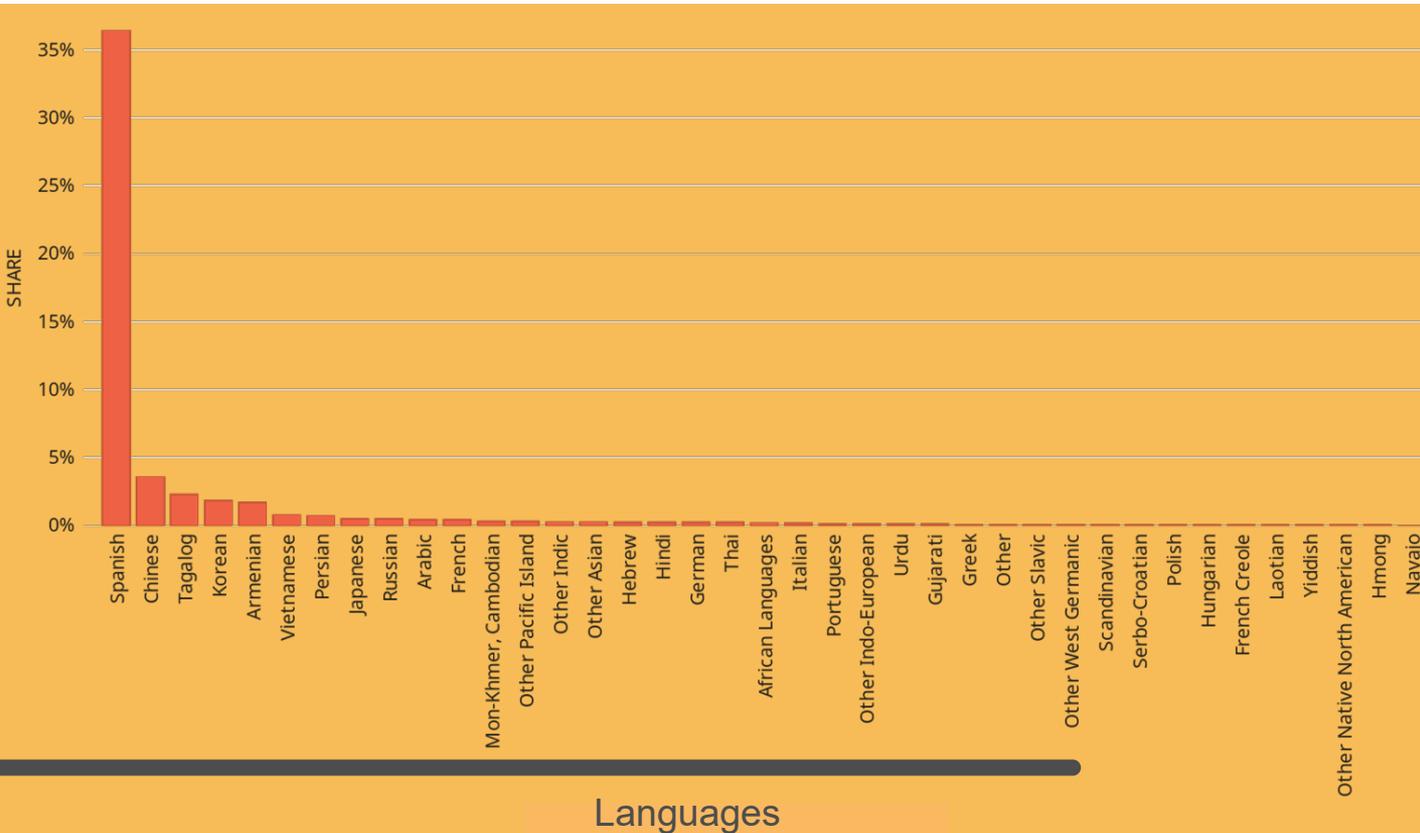
1. Develop communication strategies that help healthcare providers discuss vaccine hesitancy with their patients.
1. Making the vaccine more accessible to all communities (e.g., mobile vaccine centers, increase vaccine information accessibility).
1. Increase awareness of needle anxiety accommodations



05

LATINX OUTREACH

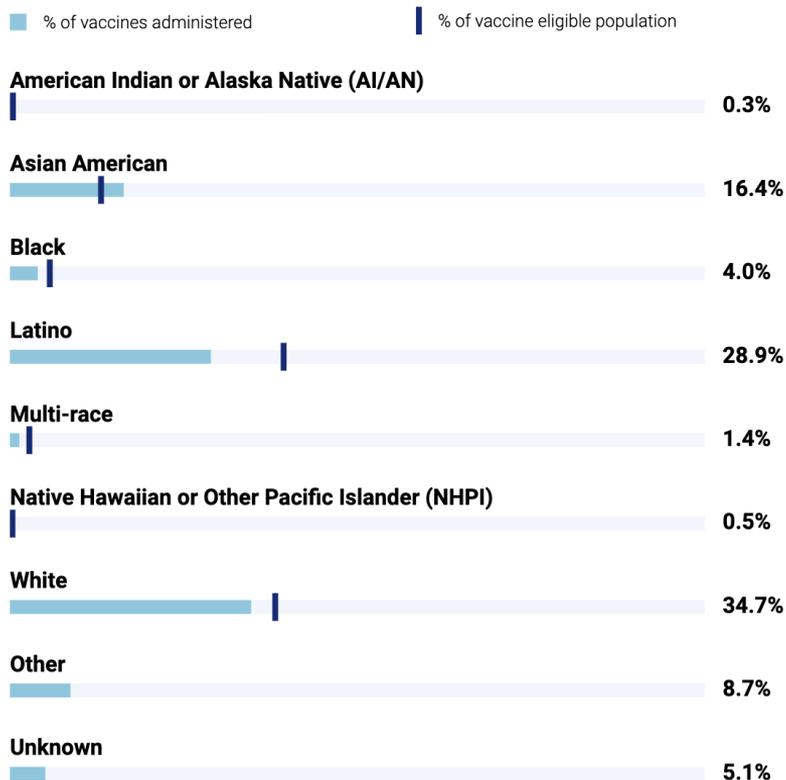
Spanish is Spoken Throughout Los Angeles



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



The Latinx Population is Underrepresented Amongst Vaccinated Californians



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



Our Spanish Language Interviews

Dr. Maria Elena
Bottazzi
Microbiologist



1



Bobby Verdugo, LCSW
Mental Health Specialist



2



Future outreach with
public health departments
with a Spanish- speaking
focus



3





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

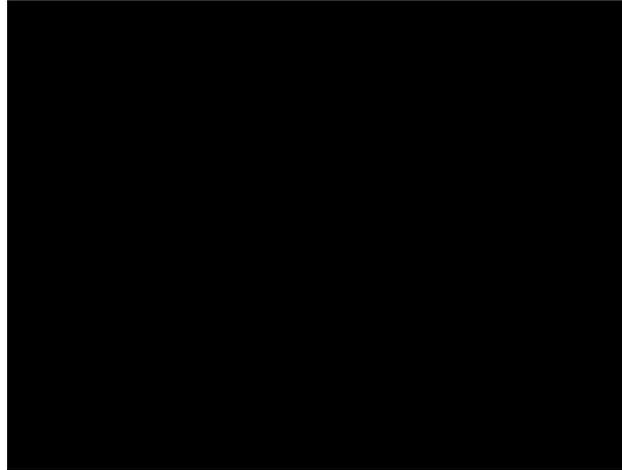
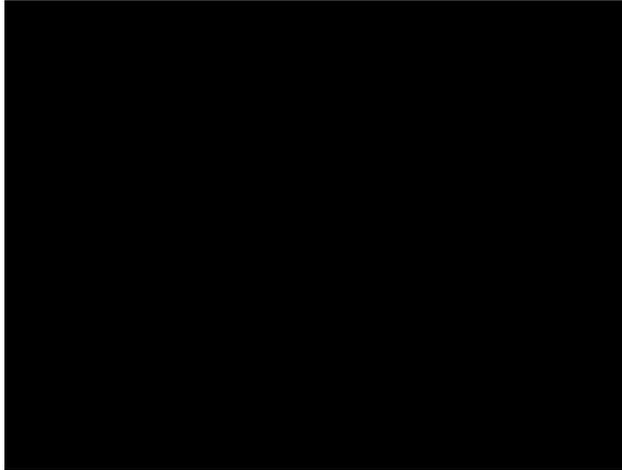


Lessons Learned: How Can We Support the Spanish Speaking Community?

Workplaces and
Community Centers

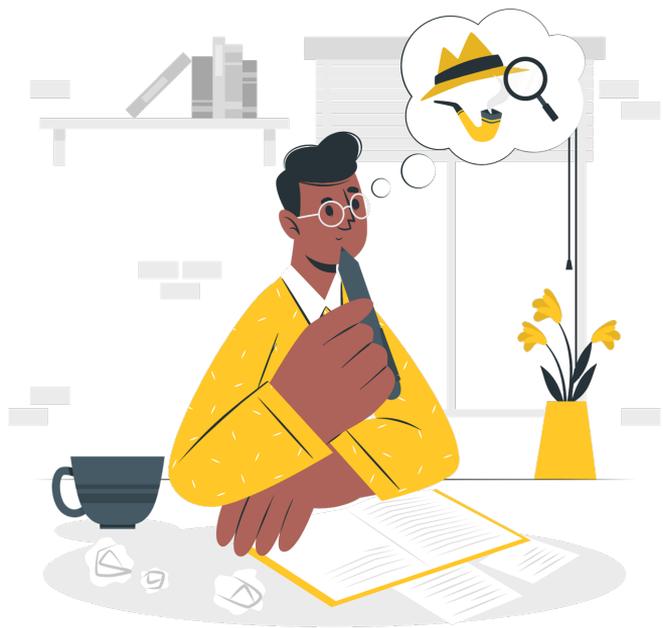
Targeted
Community Support

Non-Judgemental
Conversations



LESSONS LEARNED ON INNOVATIVE WAYS TO DISSEMINATE PUBLIC HEALTH INFORMATION





06

Blog Posts



PILLARS OF ONLINE WRITING

Creating digestible content

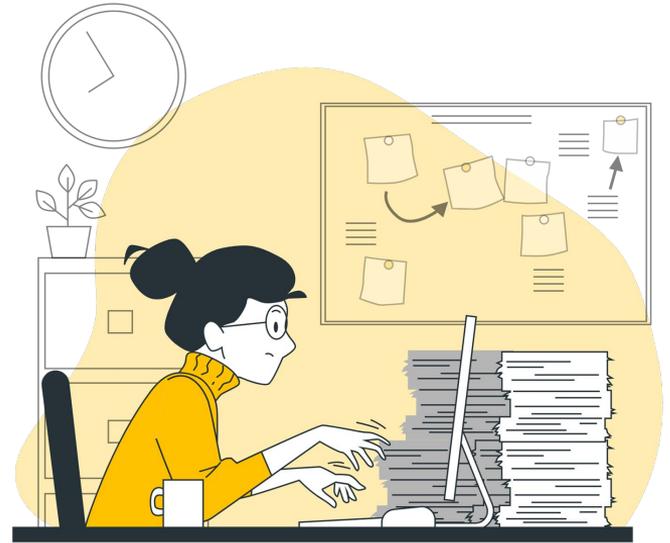
Boil down ideas so the average reader can understand complex topics.

Drawing Empathy

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

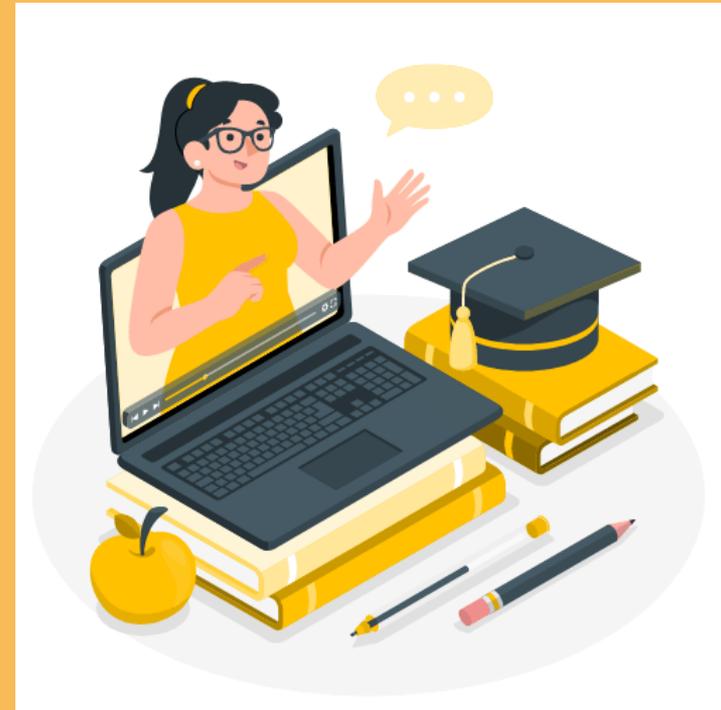
Taking a stance

Make sure readers take away something from your content



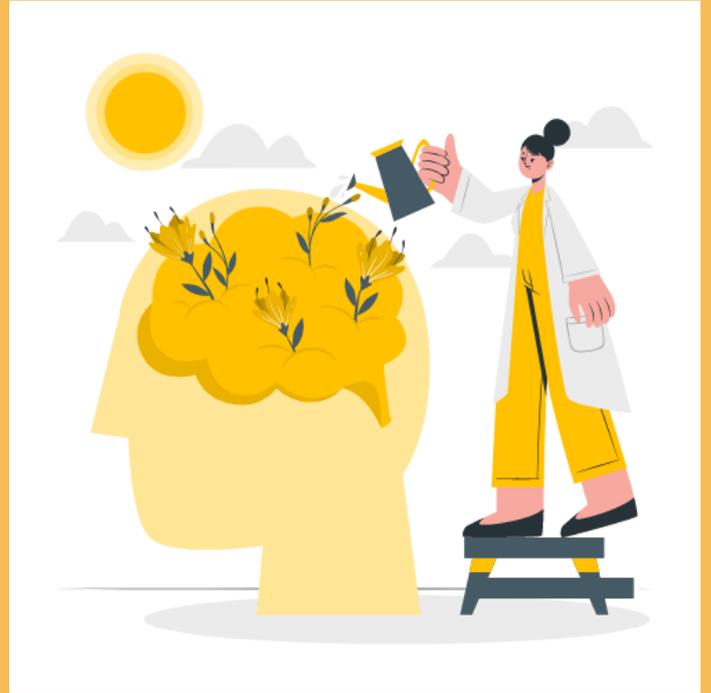
Creating Digestible Content

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



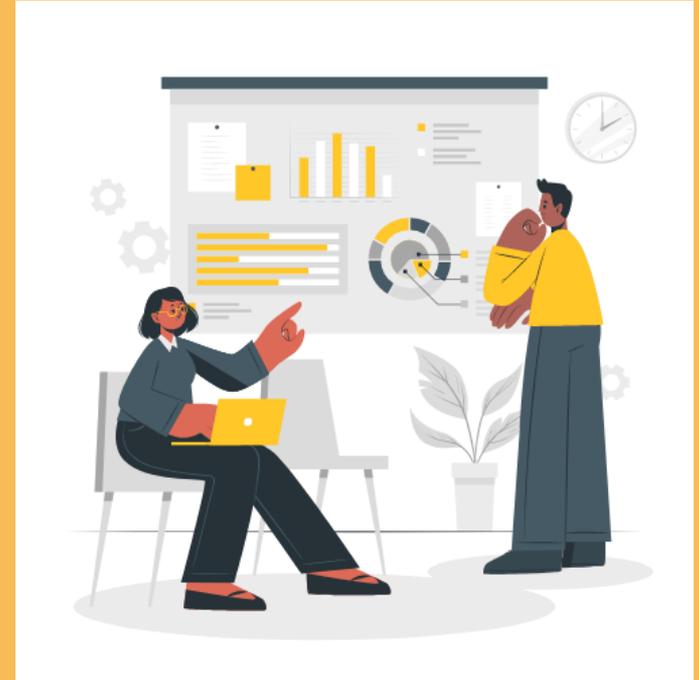
Drawing Empathy

- 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)





OUR PIECES

Tuesday, Aug. 17, 2021

DAILY BRUIN



COMMUNITY, OPINION

Op-ed: COVID-19 vaccine hesitancy is a product of structural racism



OP-ED

“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 Khorasani

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 flu vaccination rates** among the disability community during the pandemic. We at NDHC had the opportunity to interview clinicians 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.

[Read More Here](#)



Talking about Vaccine Hesitancy

By: Asal Bastani

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 vaccination 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.

[Read More Here](#)

ndhealthchats ⁴



25 Posts 85 Followers 117 Following

Neurodiversity Health Chats

Promoting health and well-being for neurodivergent communities.
Managed by the UC-LEND program.
linktr.ee/neurodiversityhealthchats

Edit Profile

- Team Tuesd...
- Interviews
- New

A grid of social media posts from the NDHC profile. The posts include:

- A post titled "DIFFERENT PATIENTS HAVE DIFFERENT MEDICAL PREFERENCES!" with an icon of a person and a speech bubble.
- A post titled "HERO IMMUNITY NEEDS YOU!" with an icon of a hand holding a shield.
- A video post featuring two women.
- A post titled "ON ACKNOWLEDG PAST INEQUITIES FACED BY UNDERSERVED COMMUNITIES:" with an icon of a scale of justice.
- A blog post titled "Having a positive vaccine experience" written by Asoil Bostany.
- A blog post titled "How to Deal with Vaccine Anxiety" written by Yafanki Ouz.

06

Social Media

Social Media Statistics

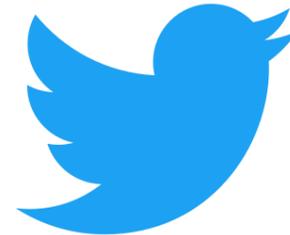
Instagram

- 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."



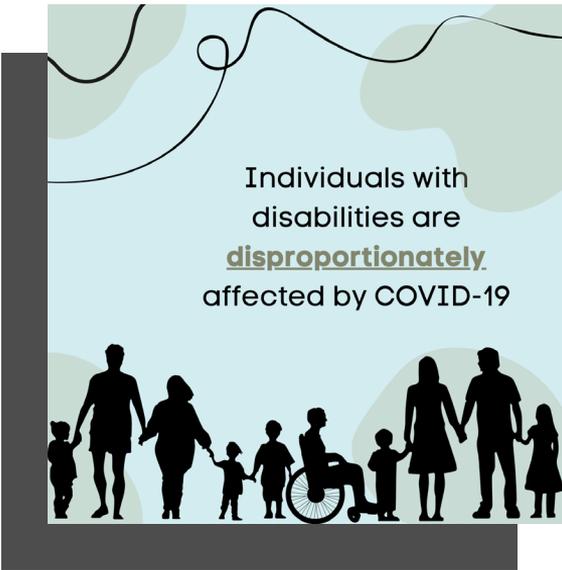
TO VIEW THE FULL
INTERVIEW, PLEASE
VISIT OUR WEBSITE

(LINK IN BIO)



Content Posts

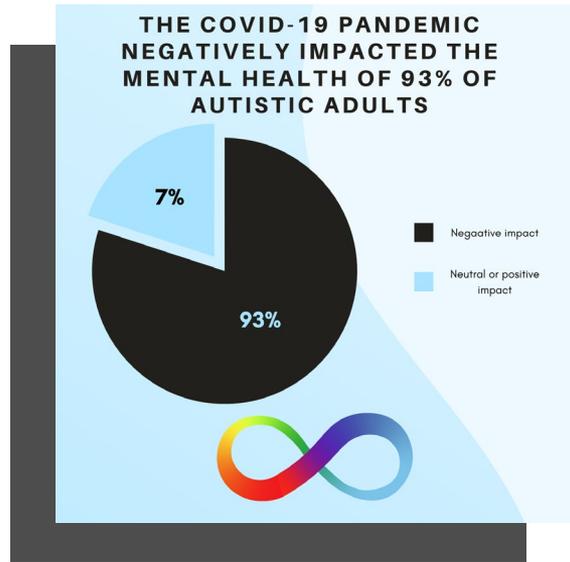
COVID-19 and the Disability Community



Disability Pride Month



IDD



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

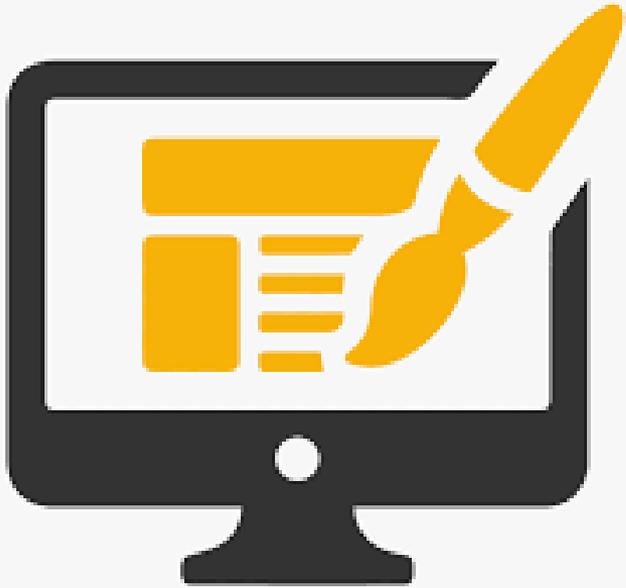
Recommendations

During COVID-19:

- Maximizing the online format

Post COVID-19:

- Continuing to grow your audience



06

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



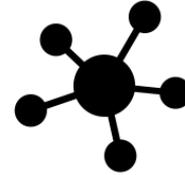
Outline Goals

- 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 & opds

<https://www.uc-lend.med.ucla.edu/blog-posts/>



Learn more

<https://connect.uclahealth.org/2021/08/11/covid-vaccine-hesitancy-people-with-disabilities/>

 Check out our content!



Link:

<https://linktr.ee/neurodiversityhealthchats>

Thank you for listening!
Any questions?