



NJ

Community

Conversations

PANDEMIC PERSPECTIVES

COMMUNITY CONVERSATIONS: NJ'S COVID-19 STORYTELLING PROJECT

Interim Report: First 500 Resident Accounts

June 2021

ABOUT THE PROJECT

Community Conversations: New Jersey's COVID-19 Storytelling Project is a statewide collective ethnography to gather and transform the personal accounts of New Jersey residents, especially those who have faced increased marginalization or greater risk as a result of the pandemic, into the building blocks of a more resilient, compassionate and Healthy New Jersey.

The project is a collaboration between the **New Jersey YMCA State Alliance**, the **New Jersey Department of Health**, and **Healthy NJ 2030**.

For more background information on the project:
<https://www.njymca.org/communityconversations>



Anywhere you see this icon, click for more information.

INTERIM REPORT COLLECTION: SUBMISSION TYPE, NUMBER OF PARTICIPANTS & FILES

	Participants	Number of Files
Creative Works	144	114
Focus Groups	111	31
Interviews	245	255
TOTAL	500	400

HEALTHY NEW JERSEY 2030 TOPIC AREAS



ACCESS TO QUALITY CARE

Lack of Financial Means: Loss of Health Insurance

Access to Care

Quality of Care

Digital Divide/Linguistic Barriers (Health Care & Telehealth)

"The most battered communities and the poorest are the ones who are paying the price in this pandemic...if we really counted all those people who stayed at home and did not go to the hospital because they did not have health insurance, and because they were afraid to pay a bill, only then would we really see that we were a very affected population."

- NJ Resident, Middlesex County [focus group translated from Spanish]

HEALTHY COMMUNITIES

Lack of Financial Means: Housing, Employment, Food, Transportation

The Social Disconnect (Social Isolation & Loneliness)

Digital Divide/Linguistic Barriers (Education, Community Resources, Workforce)

"Being homeless during COVID-19 made me feel more vulnerable to getting sick, and I was at my lowest point in life...the welfare, they should have been more caring or at least have a heart for the homeless people like myself. They had me sit in the waiting room for hours just for them to tell me, 'No, we can't help you.' I was even pregnant at the time, and they still didn't care. They couldn't even give me referrals for any programs or shelters to go to."

- NJ Resident, Union County



"It's required of me to put in extra hours at work. It even goes as far as, I'm being mandated, because a lot of nurses don't show up for work or the following shift. So, I'm mandated to stay at work, and I'm missing all this time with my son.

Working these long hours, I wasn't able to get proper rest, to eat properly, rest properly. So, I had a weakened immune system. I actually contracted [COVID], and I actually got it from work.

[...] I was trying to get some workers compensation which didn't happen, because my job wanted to say that I did not get it there. I find that very unfair."

- NJ Resident, Bergen County

HEALTHY FAMILIES

Parents Functioning as Teachers

Childcare Arrangements

Maternal Health (Pre & Post-Natal Care)

Caregiving & Support for People with Disabilities

"My kids staying at home all the time -- that was, in itself, a stressor...because a lot of my attention, whereas I was supposed to be devoted to my newborn infant, I had to switch gears and start kind of teaching my children the things that the teachers would have been teaching the kids at school...I had to do all out mom, and teacher."

- NJ Resident, Atlantic County

COVID-19 PANDEMIC IMPACT ON FAMILIES LIVING WITH DISABILITIES

Findings for school-aged students:

- Difficulty with remote learning and the abrupt change in routine
- Missed therapy; virtual speech, occupational (OT) and physical (PT) not as effective
- Developed challenging behaviors, including aggression and self-injury
- Difficulty with masks and social distancing
- Most parents willing to vaccinate
- Lost opportunities for transition services such as touring day programs, in-person community-based instruction (CBI), and vocational training
- Denied SSI, despite not being able to secure employment
- Notably, some students thrived due to removal of school anxiety

"My sister has an autistic child, and they're home. Most of his classmates have chosen to go back to class, he's in a small class, and they're not sending him.

There's millions of issues, but they have no self-time whatsoever, they have the stress of an autistic child...that just breaks my heart. There's so many people readjusting."

- NJ Resident, Burlington County

COVID-19 PANDEMIC IMPACT ON FAMILIES LIVING WITH DISABILITIES

Findings for adults:

- Needed caretakers during day program closure
- Day programs subject to the COVID Activity Level Index (CALI) report, have not reopened, may close suddenly
- No equivalent of hybrid learning
- No supported employment
- Family members able to serve as Self-Directed Employees (SDEs), some difficulty applying, inconsistent pay across agencies
- Group home residents “in prison,” onerous visitation rules with family
- Lost services, isolated, quarantined out of home
- Difficulties with keeping staff

Findings for families:

- Worked remotely, gave up jobs, paid for extra help
- Parents overwhelmed, needed medication

COVID-19 PANDEMIC IMPACT ON FAMILIES LIVING WITH DISABILITIES

Areas for further advocacy

- Find ways to provide additional respite services for severe challenging behaviors
- Open adult day centers with more consistent schedules
- Allow parents of adults to continue using their service budget to serve as SDE's, to allow for flexibility in creating a meaningful week
- Provide devices and internet service as needed for students and adults
- Allow students to access free virtual public education programs; continue hybrid learning
- Give recent graduates opportunities to recoup in-person vocational training
- Provide ways for families to personally interact with group home residents
- Reduce the wait time and requirements for children's residential placement
- Increase availability of emergency stabilization beds in NJ for individuals in behavioral crisis

HEALTHY LIVING

Mental Health Challenges/Impacts on Mental Health

Self-Care Strategies

Resources Needed – Mental & Behavioral Health Care

"My biggest fear was me getting sick, what's gonna happen with my son? There's no plan I'm able to put in place because of lack of services...if I were to take him to the ER, as was suggested many times by his school during certain episodes, I refused to do that because people in the medical facilities are not trained to deal with mental illness...and we're going to see such an increase in mental illness in the long term as a sequela to this pandemic, even within the neurotypical individuals."

- NJ Resident, Mercer County



THE GIVER, 2021

MIXED MEDIA

I am not a painter or an artist by any means. I am a pharmacist by trade. However, during this pandemic I unexpectedly felt compelled to put this piece together. This is a mixed media piece, consisting of acrylic paint, caps from the Pfizer vaccine and diluent vials associated with the 696 doses given to healthcare workers, a face mask, and a face shield. Collectively representing the personal protective equipment and resources so the healthcare worker may continue serving their community, giving their all to those in need. And in looking at this piece, you feel their drive, energy and fire to keep their patients safe. Therefore, I call this piece The Giver.

- NJ Resident, Bergen County



CROSS-CUTTING ISSUES

Equity

- Lack of financial means to support basic necessities
- Groups left out of the virus response
- Resources needed

Policy

- Resident recommendations include:
 - Increased emergency preparedness
 - Fair wage & supportive employment
 - Continued stimulus support & expanded unemployment assistance
 - Increased access to mental health services & social supports
 - Support for people with disabilities and caregivers

Resilience

- Unpredictability of pandemic
- Secondary suffering and trauma
- Social reconnect
- Acts of kindness
- Positive outlook
- Resilience
- Religion/spirituality

"I think though, if you can look at it -- I look at it from a hopeful place, because I'm so optimistic. Because this is our ground for change. We can choose to start from this place, root in a different way.

It is difficult, and it is scary...but this is a great platform to leap from and engage in this way until we can make changes and it gets better."

- NJ Resident, Burlington County

The background is a light purple color with a repeating pattern of various speech bubble and thought bubble shapes in a slightly darker shade of purple. The shapes vary in size and orientation, creating a dynamic and conversational feel.

DEMOGRAPHICS OF THE COMMUNITY CONVERSATIONS PARTICIPANTS

Figure 1: Gender of Participants

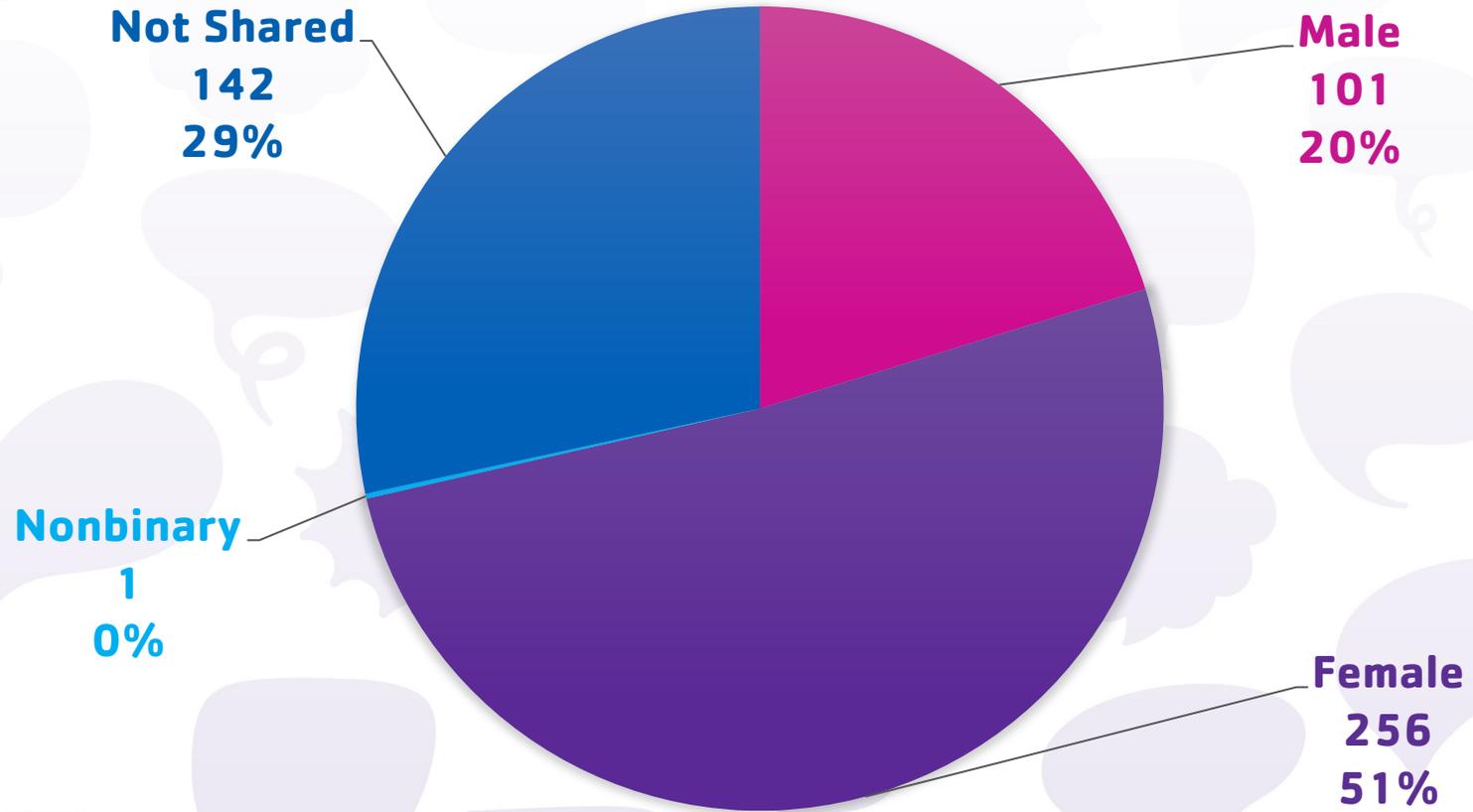


Figure 2: Age of Participants

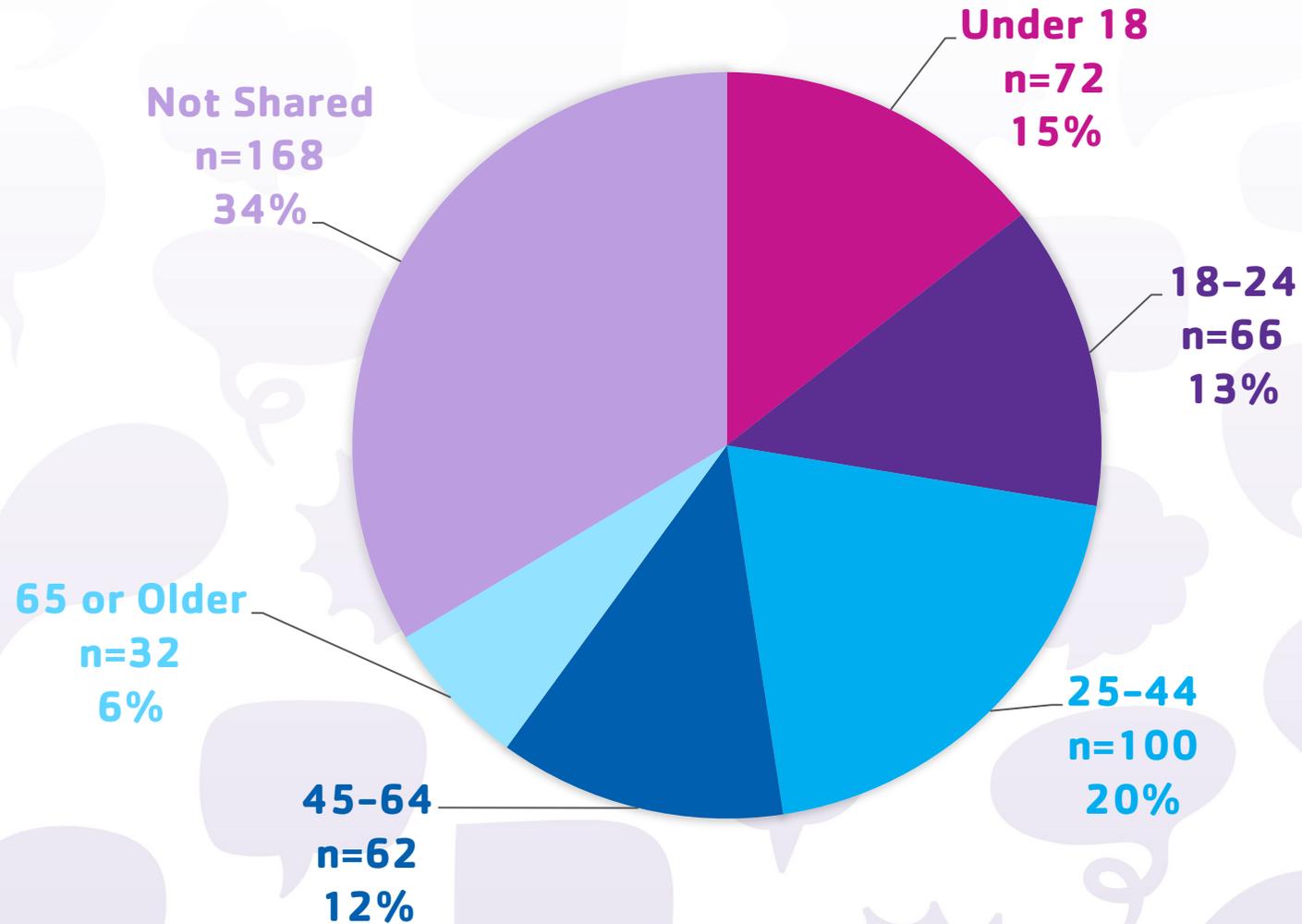
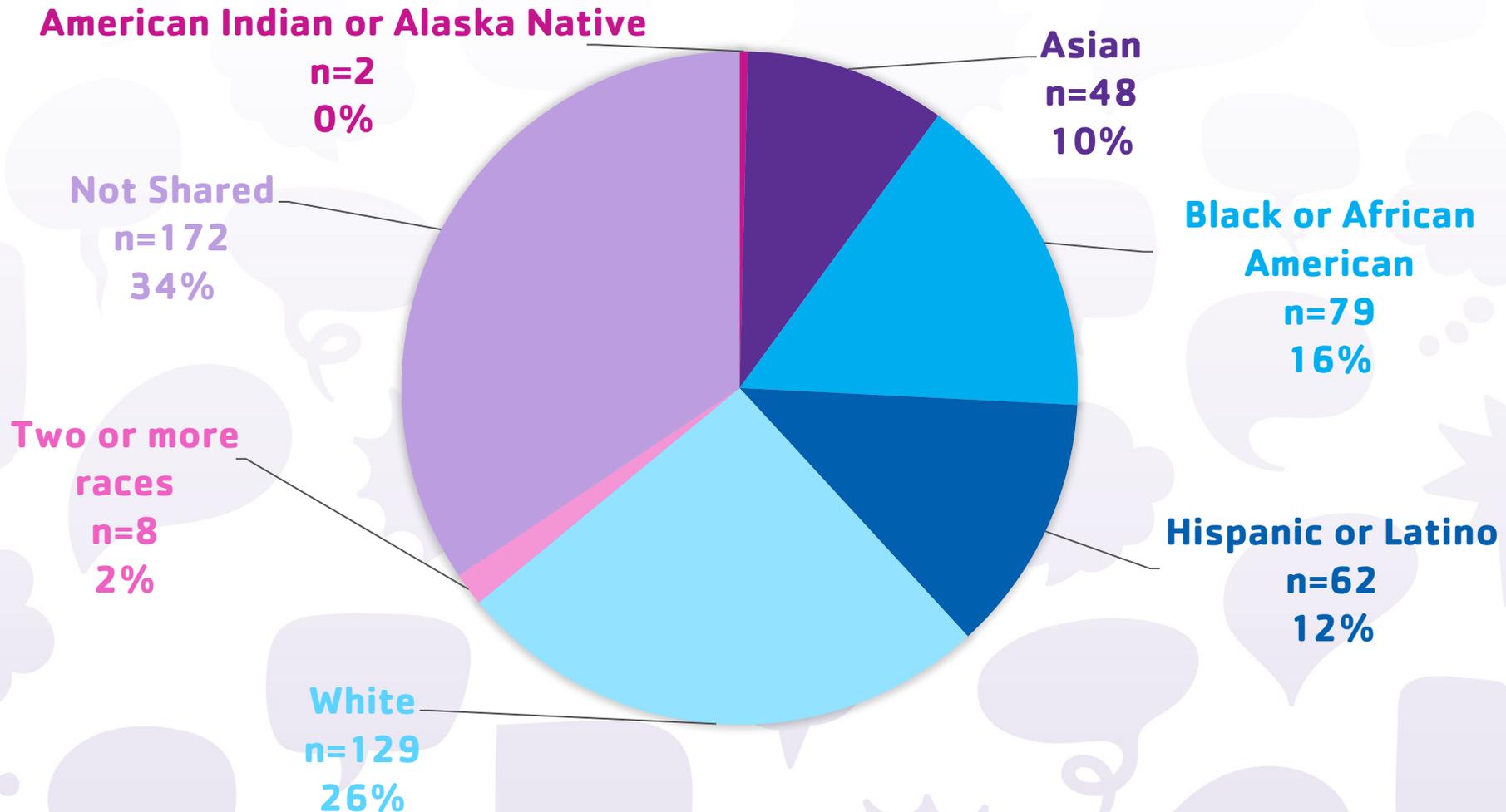


Figure 3: Race/Ethnicity of Participants



PROJECT STATUS AND NEXT STEPS

JUNE 2021: STATUS UPDATES



Theme-Based Animations

- “Digital Divide” – *completed*
- “The COVID Disconnect” – *in final production*
- “Left Out, Trapped In” – *in final production*
- “Maternal & Child Health” – *scripting*
- “Mental Health” – *scripting*
- “Youth Stories” – *coming up*



Theme Analysis

- Codebook in final development
 - *Phase I: Social Determinants of Health*
 - *Phase II: Social Ecological Model*
- Coding in NVivo software scheduled for completion August 2021
- Full report analysis coming September 2021

CULTURE OF HEALTH CONFERENCE & SHOWCASE



9TH ANNUAL CONFERENCE

Building a **Culture of Health** in New Jersey

HEALING COMMUNITIES & CONNECTING VOICES

DECEMBER 9-10, 2021 • HARRAH'S WATERFRONT CONFERENCE CENTER

CONFERENCE:

- December 9-10, 2021
- Harrah's Waterfront Convention Center
- Stories of Loss, Kindness & Resilience breakout

SHOWCASE:

- Thursday, December 9, 2021
- Community Conversations: NJ Pandemic Perspectives featuring art, poetry, music and animations
- In-person with virtual components



ACKNOWLEDGEMENTS

We extend our deepest and most heartfelt gratitude to the 582 New Jersey residents who shared their time, creativity, experiences, and/or voice in storytelling. Storytelling is a brave act of resilience, and the willingness to share struggles and survival during COVID-19 can support New Jersey's healing and learning moving forward.

FUNDERS AND COLLABORATORS



In collaboration with the [Senator Walter Rand Institute for Public Affairs at Rutgers, the State University of New Jersey-Camden](#) and the [New Jersey State Library](#).