NJ Community Conversations
PANDEMIC PERSPECTIVES

Final Report: Findings from Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project

NJ Health
New Jersey Department of Health

the YMCA

Healthy New Jersey 2030

Prepared by the Senator Walter Rand Institute for Public Affairs (WRI) at Rutgers, The State University of New Jersey – Camden

RUTGERS
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Acknowledgments

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"Our lives changed dramatically in just one day.
Everyday things that were taken for granted changed."
(Participant 021)

Introduction

This report provides overview, context, and summarized findings from participants in New Jersey who shared their personal experiences as part of ***Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project***.

The findings generated from the analysis reflect the most common themes experienced by nearly 600 participants throughout the COVID-19 pandemic. These nine themes are drawn directly from the data and speak to the perspectives of individuals in New Jersey who participated in the ***Community Conversations: Pandemic Perspectives*** project. While the themes may not be all-encompassing, they reflect raw, real-time experiences of life during a global pandemic, speaking to the challenges and unknowns that individuals faced during this time. When reviewing the nine themes that emerged from the data, three interconnected findings also surfaced: **Collective Isolation & Trauma**, **Inequalities & Disparities**, and **Unpredictability Now & Into the Future**.

These findings, offering both specific examples and broad patterns, can be used in many ways moving forward: (1) the development of additional white papers that provide a deeper examination of one or any of the themes and supporting contextual information (e.g., supporting secondary data and statistics); (2) for support in the development of local and state policy around any number of issues (e.g., worker benefits, family and child subsidies, healthcare access, and other social policies); (3) for support in the development of programs by philanthropy, private entities, and NJ state departments to more appropriately allocate resources to under-resourced neighborhoods and to community organizations working in these neighborhoods; (4) the utilization of findings by New Jersey YMCA State Alliance, New Jersey Department of Health, and Healthy New Jersey 2030 Advisory Council and Action Teams to develop policies and programs that can help to address existing gaps in services across the state; and (5) to inform recommendations and public health priorities incorporated in the New Jersey State Health Improvement Plan, Community Health Needs Assessments, and Community Health Improvement Plans. As illustrated in this report, the challenges confronting our state during and after this pandemic are complicated and require nuanced and multilayered solutions.

Overview of Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project

Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project gathered, documented, and analyzed the personal accounts of New Jersey participants during the COVID-19 pandemic. The project aimed to go beyond the numbers and capture the experiences of individuals in New Jersey during a period of unprecedented change, especially those who have faced increased marginalization or greater risk as a result of the pandemic. Led by New Jersey YMCA State Alliance, the process was diverse, decentralized, and inclusive. ***Community Conversations: Pandemic Perspectives*** incorporated interviews, focus groups, and a wide variety of creative works from participants in all 21 counties across the state. The project was a collaboration between New Jersey YMCA State Alliance, New Jersey Department of Health, and Healthy New Jersey 2030. Funding was generously provided by the Russell Berrie Foundation, Robert Wood Johnson Foundation, New Jersey Department of Health, and New Jersey Health Initiatives.

The Senator Walter Rand Institute for Public Affairs (WRI), an applied research and public service center on the Camden campus of Rutgers, The State University of New Jersey, analyzed the data to identify key themes and disparities that will inform actionable recommendations for improving public health.

Background Information: Partnership between New Jersey YMCA State Alliance and New Jersey Department of Health

From late 2019 to early 2020, New Jersey YMCA State Alliance (NJYSA) partnered with New Jersey Department of Health (NJDOH), Office of Minority and Multicultural Health (OMMH) to conduct its annual health equity forums for 2020. Co-facilitated by the Healthy New Jersey 2030 (HNJ2030) Advisory Council, the forums, titled "Health Equity Community Conversations," were to be conducted in April and May 2020 with groups underrepresented in public health priorities. Through these conversations, resident voices would become the foundation in developing evidence-based, 10-year objectives in New Jersey's State Health Improvement Plan (NJSHIP), by learning about how HNJ2030's focus issues impact residents and how they should be improved. Due to the rapid onset and rise of COVID-19 cases in New Jersey, the forums were placed on hold and discussions pivoted to understanding the pandemic's heightened impact

on populations already experiencing vulnerability, as well as what lessons could be incorporated in future public health policy and practice.

Witnessing the impacts of inequity and injustice during the pandemic through statistical data and experience, NJYSA collaborated with NJDOH, Office of Population Health (OPH) and OMMH, and the HNJ2030 Coordinating Committee and Advisory Council, to build a comprehensive approach for learning and becoming more responsive to the disparities exposed and exacerbated by COVID-19. To achieve this vision with equity at the forefront, a qualitative methodology through individual and community-based storytelling was developed, to capture and elevate the voices of community members experiencing increased marginalization and vulnerability during the pandemic.

In June 2020, NJYSA worked in coordination with NJDOH to identify key populations prioritized for outreach and developed a set of 26 guiding questions to support the thematic analysis of resident experiences by WRI. Through a community-centered process of outreach and engagement, NJYSA leveraged new and existing relationships with organizations around the state, including its network of YMCA associations and branches, grantees, community partners, institutions of higher learning, advocacy and support groups, and other public health-related groups and networks. In addition, NJYSA developed a webpage, published social media posts, and created storytelling resources and materials in multiple languages to encourage individuals to gather stories from their communities or share their own. Through these relationships and efforts, the project progressed into a robust statewide collaboration, uplifting the voices of residents, including emergency and essential workers, staff and volunteers at community-based organizations and health centers, and groups and individuals active in public service.

Community Conversations: Pandemic Perspectives documented 584 resident accounts from August 2020 through March 2021 as virtual and on-site interviews, focus groups, written narratives, journals, reports, poetry, short films, music, artwork, and other forms of storytelling.

By integrating the direct experiences and feedback of residents into HNJ2030's development process, NJYSA, NJDOH, and the HNJ2030 Advisory Council and Action Teams will be better equipped to develop supportive policies and programs that offset gaps in strategy and services in under-resourced areas. The New Jersey State Health Improvement Plan (NJSHIP), Community Health Needs Assessments (CHNAs), and Community Health Improvement Plans (CHIPs) can all benefit from this data to better inform actionable strategies. In so doing, state and local health systems can be strengthened through a collaborative approach, informed and guided by residents, to better understand and address the priority health needs of New Jersey communities.

Research Design: Qualitative Data Collection Methods

Community Conversations: Pandemic Perspectives was a statewide collective phenomenology to gather and transform the personal accounts of New Jersey community members, especially those who have faced increased marginalization or greater risk as a result of the COVID-19 pandemic, into the building blocks of a more resilient, supportive, compassionate, and healthy New Jersey.

The project was designed to utilize qualitative data collection techniques as they are "our best method for capturing social responses to this pandemic," (Teti et al., 2020, p. 1). Qualitative research methodologies help to understand the reasons for behaviors, social interactions, and the ways in which individuals make sense of what is happening around them (Leach et al., 2020), while bringing light to the unforeseen conditions and intersecting inequalities (Cookson & Fuentes, 2020). Qualitative research can play a crucial role in highlighting experiences during difficult and challenging situations (Kadzin, 2003) and can provide clarity on the various aspects of human behavior such as values, perspectives, and contextual circumstances (Johns Hopkins Medicine, n.d.). With qualitative methodologies, insight can be gained regarding the social responses of this pandemic, including unfolding events and traumatic experiences. ***Community Conversations: Pandemic Perspectives*** goes beyond the numbers to create a comprehensive, statewide understanding of how the COVID-19 pandemic has impacted individuals.

This project aims to not only shed light on how we can move forward as a state with effective policies and recommendations for community leaders, but also works to ensure that resident voices are heard, especially those in groups underrepresented in public health decision making. NJYSA recognized that individuals have different preferences and levels of comfort with sharing difficult experiences, emphasizing why the utilization of diverse forms of data collection was so vital to the larger conversation around the impacts of COVID-19. This project allowed for data to better assist in explaining, addressing, and planning for the ongoing COVID-19 pandemic and future crises (Miles & Huberman, 1994; Teti et al, 2020).

For this project, NJYSA served as the "boots on the ground" partner by reaching out to communities in all 21 New Jersey counties. New Jersey, a state with an incredibly diverse population, has a valuable story to tell, and the heart of this project is to elevate the voices of community members who have been historically underrepresented and marginalized, or have faced higher risk of contracting or dying from COVID-19. These are the voices largely left out of the pandemic response and narrative, and are the voices that must be heard if we are to build a just and equitable response to truly meet all New Jersey residents' health needs.

Data Collection Strategies

NJYSA worked with many partners and collaborators to gather submissions from participants across the state of New Jersey, with a minimum of three participants from all 21 counties. The submissions consisted of interviews (audio, visual, or written), focus groups (audio or visual), or creative works (poetry, vlogs, essays, artwork, short films, journaling, and more).

The table below highlights the types of submissions and the number of participants and files.[1]

Table 1: Submission Type, Number of Participants & Files

	Participants	Number of Files
Creative Works	199	130
Focus Groups	119	34
Interviews	266	290
Total	**584**	**454**

Qualitative Data Analysis Procedures

For this project, NJYSA gathered data on specific experiences related to the COVID-19 pandemic from August 2020 through March 2021. WRI analyzed the data to uncover common themes and key disparities in experiences from residents, public servants, and essential workers across the state. The focus of the analysis was to identify actionable conclusions that can support policy and programs aimed at addressing existing health disparities.

NJYSA obtained consent prior to participants engaging in the data collection process and the goal of the project was fully explained to prospective participants. Through participation, respondents were asked to reflect upon their experiences during the COVID-19 pandemic. Data collection continued until data saturation was reached (see Seidman, 2006) and until closure of the data collection period on March 31, 2021. NJYSA collected all submitted data and shared the de-identified submissions with WRI. Participant numbers have been given to all respondents who are quoted in this report. WRI submitted and obtained approval from the Rutgers University Institutional Review Board (IRB).[2]

1 The NJYSA collected a total of 584 responses that WRI analyzed for inclusion into the final report.

2 The Institutional Review Board (IRB) process at Rutgers, The State University of New Jersey implements the rules stipulated by federal agency regulation of human subjects research. All research at Rutgers University must be completed in accordance with these guidelines. The Rutgers University IRB has the authority to approve, require modifications in planned research prior to approval, or disapprove research. Approval was granted for WRI's data analysis of this project on November 2, 2020 (Protocol #Pro2020002677).

Data from ***Community Conversations: Pandemic Perspectives*** was entirely qualitative, and described participants' real experiences and perspectives about the COVID-19 pandemic and its impact on their lives. Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 1994, p. 2). A good example of a qualitative research method would be unstructured interviews or semi-structured interviews, both of which were used within this project by facilitators, which generate qualitative data through the use of open questions. This allows the participant to respond in detail and choose their own words to represent their experiences and perspectives. This methodology helps the facilitator to develop a real sense of the participant's understanding of a situation.

As a result, open coding was used to identify themes across the data. When open coding data, WRI researchers identify individual codes within set lengths of data; sometimes at the phrase level, but most often at the sentence or multi-sentence level. This level of analysis allows us to understand the ways that themes are present across the breadth of data. The most appropriate way to interpret open coded data is at the theme and sub-theme levels, presenting data in sections organized by themes with descriptions of the data and sub-themes within those sections. Open coding and thematic presentation are most effective for ***Community Conversations: Pandemic Perspectives*** data as it gives us the broadest understanding of how people discussed their experience with the COVID-19 pandemic, and provides rich descriptions through statements identifying themes and sub-themes, with examples from direct quotes. This may also be useful in developing practices and policies to address concerns and challenges, as well as identifying and employing strengths. In addition, qualitative analysis allows for ambiguities and contradictions in the data, which are a reflection of social reality (Denscombe, 2010).

Unlike in standardized surveys, valuable information in qualitative research is often volunteered, but not solicited routinely. "As such, any count of the number of respondents who gave certain information is probably an undercount," (Padgett, 2016, p. 323). With regards to ***Community Conversations: Pandemic Perspectives***, the participants were not all asked the same questions in the same order, and NJYSA created a set of guiding open-ended questions to learn about the participants' perspectives about the COVID-19 pandemic. Thus, if not all participants have been asked exactly the same questions in the same way, reporting or alluding to the frequency of a given response or emergent theme will most likely misrepresent the data, even within the sample studied. In addition, the use of numbers tends to detract from the more valuable, detailed, and nuanced data that are collected in qualitative work (Ritchie & Lewis, 2003). Qualitative research focuses specifically on individuals, beliefs, behaviors, perspectives, and experiences, which can be difficult to quantify. The data was examined using the NVivo 12 data management and analysis software (Bazeley, 2007), detailed in Appendix D. Please reference Appendices B, C, and E for additional information pertaining to the qualitative data analysis procedures.

Demographics of Community Conversations Participants

Nearly 600 (N=584) individuals in New Jersey participated in ***Community Conversations: Pandemic Perspectives.*** The charts below detail demographic information provided by participants.

Figure 1: County of Residence[3]

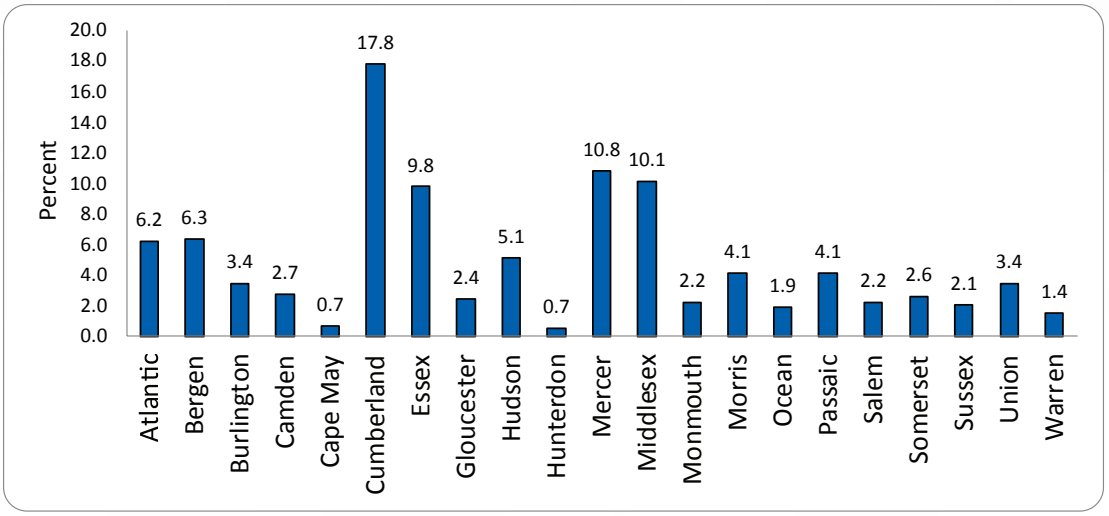
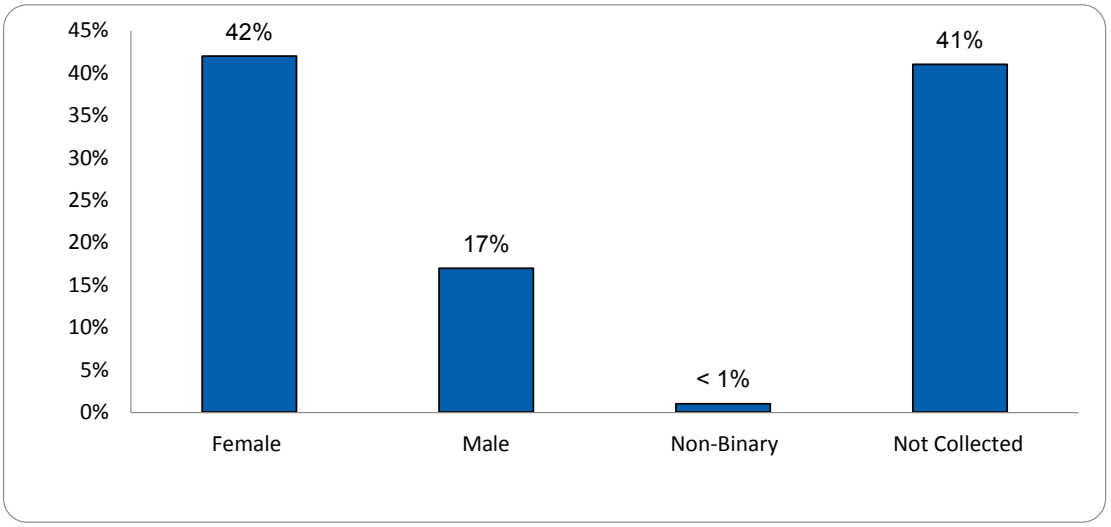


Figure 2: Participant Gender



3 Note there were 13 participants that participated, worked, or studied in New Jersey, but did not reside in New Jersey. The county where they worked or studied was noted in the chart.

Figure 3: Participant Age

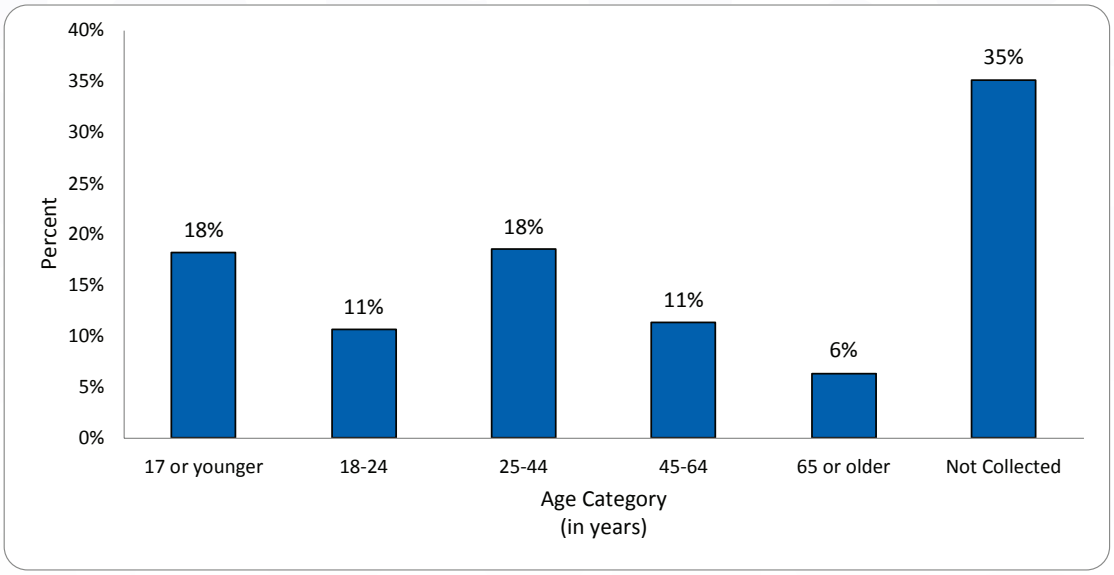
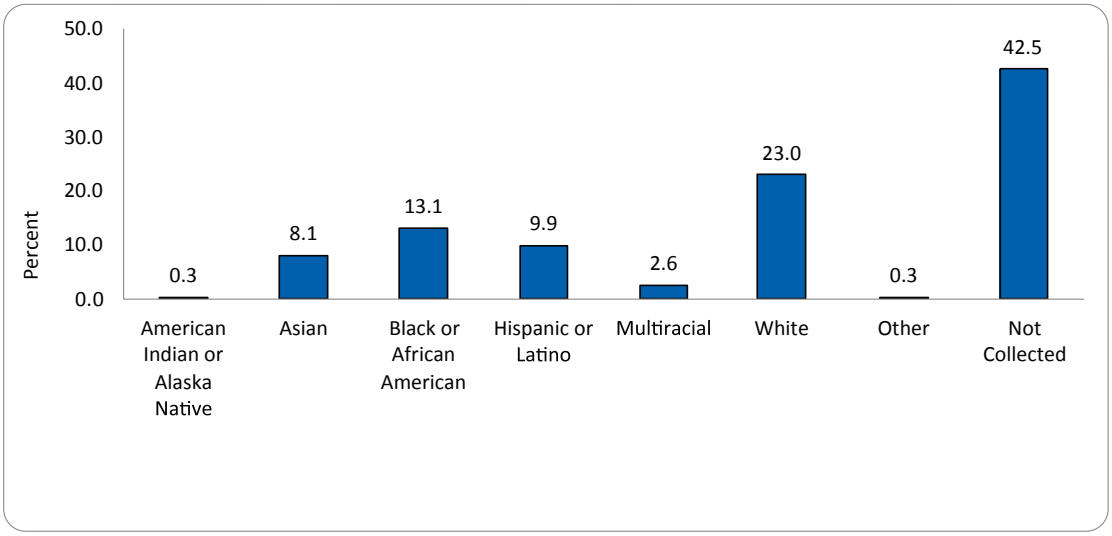


Figure 4: Self-Identification of Race/Ethnicity of the Participants



Context for the Data Collection: Disparate Impacts, Needs, & Disruptions (August 2020 – March 2021)

The data collected for this project were gathered and synthesized during the COVID-19 pandemic, with the immense challenges and shifts in daily life ongoing at the time this report was written. By the end of March 2021, the COVID-19 pandemic resulted in over 30 million cases and 525,000 deaths in the United States since March 2020.[4] In the same time period, New Jersey alone had around 887,000 cases and over 24,000 deaths.[5] There have been lockdowns, closures, economic instability, and dramatic spikes in unemployment in combination with the physical and emotional effects of the virus's spread.

Rates of hunger and poverty, which nationally had been on the decline, climbed up again during this time (PBS Newshour, 2021). According to the 2020 U.S. Census Bureau Household Pulse Survey, more than half of New Jersey residents (53%) reported a loss of employment income since the pandemic's beginning and the majority of respondents (56%) reported difficulties paying for usual household expenses during the pandemic (Kapahi, 2020a; U.S. Census Bureau, 2019 & 2020a). These challenges were particularly acute for working families. In 2019, approximately one in ten families with children in New Jersey lived in poverty, and in 2020, households with children were twice as likely (19%) to report that it was "very difficult" to cover usual expenses during the last seven days compared to households without children (9%) (Kapahi, 2020b; U.S. Census Bureau, 2019 & 2020b). In addition, while COVID-19 caused unprecedented economic disruptions across the state, households with children were 23% more likely to report a loss of employment income since the beginning of the state's quarantine in March 2020 than households without children. The data also suggest this impact disproportionately affected Black and Latinx residents, and households with lower incomes (Kapahi, 2020; U.S. Census Bureau, 2019 & 2020).

With the introduction of the national COVID-19 vaccination program in 2021, cases of COVID-19 and COVID-19-associated deaths and hospitalizations declined in New Jersey, and Governor Murphy shared in the spring of 2021 that there was a "new light on the horizon" in terms of containing the virus. Yet, the rise of the Delta variant during the summer of 2021, as well as continued health and economic challenges, hindered the path to recovery. There remains concern about the harm disparately inflicted on marginalized groups during the pandemic, "underscoring the need for more investment in public health systems" (Stainton, 2021). However, studies have shown disproportionate impacts continue regarding testing, access to care, and capacity to manage the COVID-19 pandemic in New Jersey.

Unequivocally, the pandemic has exacerbated socioeconomic inequities across racial lines in New Jersey. Systemic racism and disparities persist in the healthcare system, housing, and employment, leading to increased vulnerability and disproportionate amounts of cases, hospitalizations, and deaths due to COVID-19 (Holom-Trundy, 2020). Across the state, Black and Latinx residents have been more likely to contract and die from COVID-19 in comparison to white residents, according to age-adjusted data, while

4 At the time this report was written in September 2021, there were over 40 million cases in the United States and over 655,000 deaths.

5 See https://coronavirus.jhu.edu/region/us/new-jersey for New Jersey specific data.

also experiencing the largest rates of unemployment and a higher likelihood of reporting food and housing insecurity (Holom-Trundy, 2020). Racial disparities in access to health insurance further exacerbate this issue, as 2020 data from the U.S. Census Bureau Household Pulse Survey revealed Latinx residents were three times more likely than white residents to report not having health insurance, with Black residents twice as likely (Holom-Trundy, 2020). These disparities create "dual crises: residents of color having a greater likelihood of contracting the virus due to conditions beyond their control…while also facing the devastating impact on long term health and finances," creating even greater inequities post-COVID-19 (Holom-Trundy, 2020).

Before the pandemic reached New Jersey, the state's economy had an expansive service-based industry, according to the New Jersey Department of Labor and Workforce Development (NJDOL). Many workers in the healthcare, grocery, and delivery industries worked amidst precarious health dangers or faced additional health risks, and often were not offered paid time off and sick leave, or proper personal protective equipment (PPE) while on the job (Senator Walter Rand Institute for Public Affairs, 2020). Employees in these frontline industries are disproportionately likely to be low-wage workers, with about a fifth employed in each of the entertainment, accommodation, food service, and retail industries, and another tenth in service or construction industries (Kaiser Family Foundation, 2020). Of the groups in New Jersey most affected by job loss, based on unemployment claim data from March to August 2020, workers were more likely to be women; more likely to be of African American or Hispanic descent; and more likely to work in industries such as office administration, sales, transportation, food services, and personal services (New Jersey Department of Labor and Workforce Development, 2020, p. 5).

Access to food was also strained during the pandemic. According to Feeding America (2021), in 2019, 34 million people lived in poverty with more than 35 million people facing hunger in the U.S., including 10 million children. The number of individuals experiencing food insecurity increased during the pandemic to more than 42 million people, 13 million of whom are children. In New Jersey, food insecurity – or unstable access to healthy foods – was expected to increase to over 56% of pre-pandemic levels, growing to be about 10% higher than in neighboring states like New York and Pennsylvania. While six counties accounted for almost half of all increases in food insecurity (Monmouth, Ocean, Hudson, Essex, Middlesex, and Bergen), every county experienced increases, some nearly doubling their pre-pandemic levels (Stampas, 2020).

Another basic need – housing – has been greatly impacted by the pandemic. According to the New Jersey State Judiciary, there were "around 60,000 evictions pending across the state" in March 2021, and it was projected by the president of the New Jersey Tenants Association that this number is likely only a fraction of evictions that will be filed during the pandemic (Guion, 2021). This could result in a mass eviction crisis if the State of New Jersey does not take additional actions to assist renters. On April 21, 2021, the New Jersey Courts released recommendations to reform how courts handle landlord-tenant matters and to address the impending flood of cases they will be asked to hear once a statewide moratorium on evictions is lifted (NJ Courts, 2021a; NJ Courts, 2021b). Governor Murphy signed another pair of bills in August 2021 stating New Jersey's eviction moratorium will end early for families above a certain income threshold, and made confidential some landlord-tenant legal actions filed during the pandemic emergency as of August 31, 2021 (Johnson, 2021). Renters making less than 80% of the area's median income were

to be shielded from eviction through December 31, 2021, while those with income above 80% of the median saw the moratorium end on August 31. The bill also provided $750 million in aid for residents who have struggled to keep up with rent and utility bills during the pandemic.

Moreover, political polarization has increased during the pandemic and shaped individual and local government public health responses (Maset, 2021). Using Gallup data, researchers found that political party support was the most important variable in explaining attitudes and behaviors around "levels of fear over COVID-19, social distancing, mask-wearing, visiting work, and the scope of expected economic and social distribution," (Rothwell & Makridis, 2020, p.2), even more so than local infection levels or other demographic variables. According to the American Psychological Association (2020), the 2020 election was a source of stress for more Americans than the 2016 presidential race, regardless of political affiliation.

All of these compounding unknowns and stressors during the pandemic have impacted the mental health of many New Jersey residents. In New Jersey, 42% of adults who responded to the Census Bureau's Household Pulse Survey between January 20, 2021 and February 1, 2021 reported symptoms of anxiety or depression (CHART, 2021). The survey data also show the impact of job loss on mental health. Half of New Jersey residents who reported losing their job in the pandemic said they experienced anxiety or depression symptoms, compared with 34.2% of those who did not lose their job. The mental health impacts of the COVID-19 pandemic have been felt across the U.S., as according to a health tracking poll from the Kaiser Family Foundation, approximately 40% of Americans have reported feeling worry and stress related to the threat of COVID-19 (Berg, 2021).

The last year has shone a light on racial inequities, political strife, and economic inequalities in our country, and how they intertwine (*New York Times*, 2021). At this point in the pandemic, racial, structural, and economic inequities have been exposed, and the voices highlighted in this report offer direct experience and context for building a healthier New Jersey. Each of these elements have played a part in the personal stories documented in ***Community Conversations: Pandemic Perspectives***, revealing that there is much to be done if we are faced with similar global and national public health crises in the future.

Artwork by Participant 291

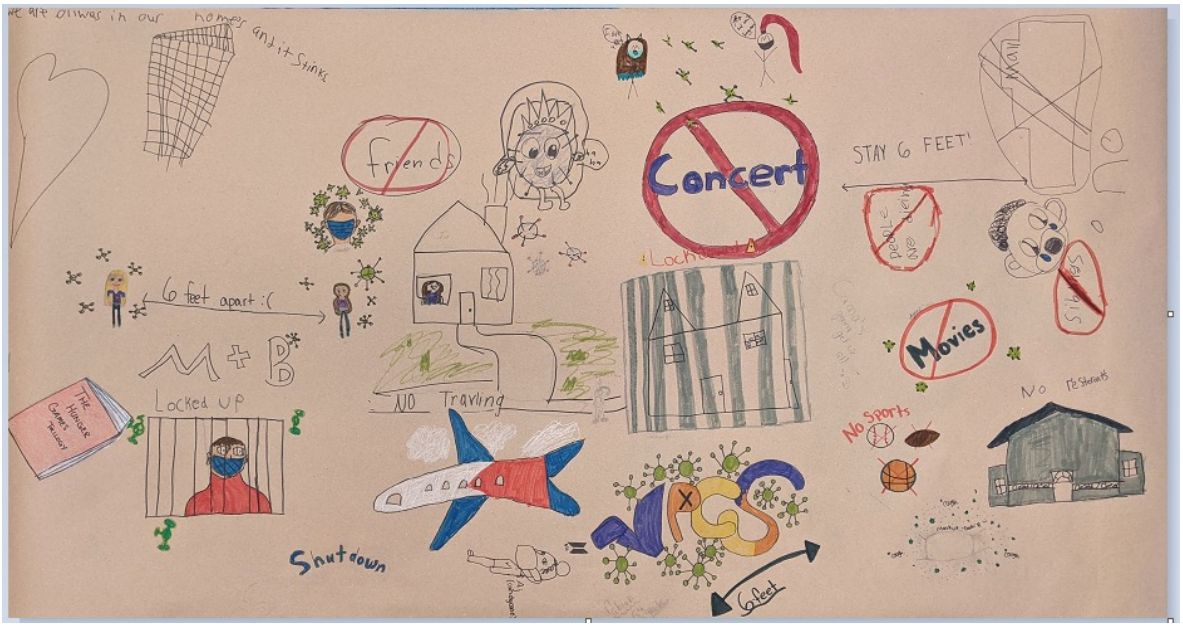
"Covid Can'ts"

Acrylic paint

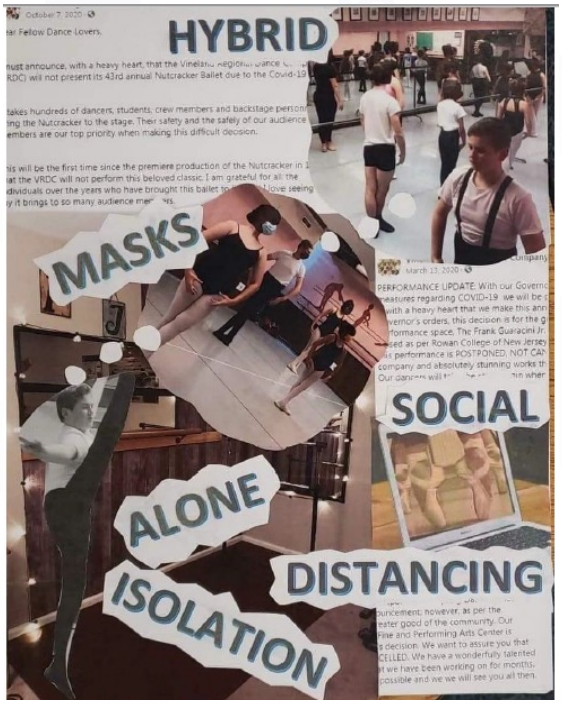
1/5/2021-1/28/2021

Once lockdown happened everything started to close down, and my life changed dramatically. I wrote down the things that I miss most about pre-covid times. Things that I enjoyed doing and now can't do as frequently or at all.

"We are apart but we're never alone."
(Participant 247)



Artwork by Participants 528-549



Artwork by Participant 318

Photo by Participant 214

"There will be a lot of healing to do physically and mentally post-COVID-19."
(Participant 237)

"COVID takes you further away from the people who you're close to."
(Participant 032)

Findings: New Jersey Resident-Informed Themes

This project collected data to both inform future health programming and policy, and provide invaluable documentation of the unfiltered and raw experiences of New Jersey community members during an unparalleled global pandemic. The stories submitted were analyzed through the Social Determinants of Health Categorization in the Robert Wood Johnson Foundation's County Health Rankings & Roadmaps and Healthy People 2030 framework. The themes that emerged include:

Table 2: Themes and References in the Data

Theme	Number of References
Mental Health	3,889
Social and Economic Factors	3,515
Clinical Care & Healthcare	3,377
Socialization	2,834
Perceptions of Residents and Societal Views/ Responses	1,155
Those Left Out of the Virus Response	961
Resources Needed and Recommendations	756
Vaccine for COVID-19	499
Physical Environment	458

Each of the above themes and their associated sub-themes (which are documented in the Table of Contents) will be discussed in this report.

Furthermore, the findings from participants' experiences contain much overlap, illustrating the interconnected nature of health and a collective story during the pandemic. The framework used to classify and analyze the data can generate compelling conversations around residents' needs and inform decisions on programs and policies that support the health of New Jersey community members.

Three overlapping themes emerged from the findings: **Collective Isolation & Trauma**, **Inequalities & Disparities**, and **Unpredictability Now & Into the Future**. These overlapping findings resonated across many of the participants' experiences and are evident throughout the main themes listed above.

Participants discussed the feelings of **Collective Isolation & Trauma** they experienced during the COVID-19 pandemic. Collectively, participants experienced constant stress, grief, fear, and sadness at the amount of death and sickness pervasive throughout New Jersey and the nation. Participants spoke in stark terms about the impacts of isolation, including extreme loneliness, and the severe negative impacts on their mental health.

Inequalities & Disparities cut across all themes and were highlighted in various facets of life – healthcare, access to transportation, access to food, access to housing, mental health, and education, particularly for those who felt left out of the pandemic response. It is evident that not all New Jersey

residents were treated equitably during the COVID-19 pandemic, and residents' experiences spoke to persisting inequities, as well as disproportionate access to and the allocation of resources.

Unpredictability Now & Into the Future was the third overlapping theme across the data. Participants expressed feeling much uncertainty about the virus, social gathering mandates, financial concerns, and misinformation. They also shared a fear of the emotional, medical, and financial burdens of the pandemic on themselves, their loved ones, and those in their communities. This unpredictability was a constant presence throughout the pandemic, and continues as participants ponder the prolonged pandemic and the potential impact of future emergencies.

Together with the findings gleaned from these overlapping themes, the data serve as an incredibly rich resource of direct reflections during a global pandemic. The stories and information shared by residents represents their experiences, perceptions, and observations during this time, and amassing this information into one place, as a living document and a time capsule – for future conversations, learning, and additional data analysis – is invaluable, particularly as the pandemic continues.

Artwork by Participant 482

"The Giver"

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."

Clinical Care & Healthcare

COVID-19 Health Behaviors

Amidst the COVID-19 pandemic, uncertainty, lack of information, and ever-evolving viral strains have plagued the country, and the world, for over two years. At the start of the pandemic, little information was available, and the emergence of the virus brought about many unknowns and confusion. What was known about circumstances of viral spread and effective preventative measures gradually evolved over time as experts and healthcare professionals began to gain more knowledge and understanding about COVID-19. As a result, certain health practices and behaviors were adopted to bolster protection in the early days of the pandemic and continued as vaccines were under development.

COVID-19 health behaviors – such as mask-wearing, social distancing, and handwashing – have since become normalized practices for many Americans. Many states across the country introduced mandates requiring individuals over the age of two to wear a mask in public areas in an attempt to reduce the spread of the virus. Masks were proven effective in preventing individual wearers from spreading pathogens to others, and as a result, many public health professionals and decision-makers recommended that individuals wear them prior to, and following, vaccine rollouts.

While many participants engaged in mask-wearing without hesitation, other individuals opposed doing so entirely, stating they do not believe masks are beneficial. Some participants admitted to avoiding friends and family who openly do not wear masks in order to keep themselves safe. In some cases, apprehension to engage in pandemic health-related behaviors formed a divide between people. Those who did partake in said behaviors have expressed disinterest in interacting with those who did not, and vice versa.

"I haven't visited my family in a while because, when I go, they don't really follow social distancing guidelines, they don't wear masks together. I'm talking about my family, like my mom, my brothers, and then my cousins and my aunts who, for me, they are a really big part of my life, and social gatherings with them was huge. But once March hit, and those stay-at-home orders started, like, I haven't seen them. Unless we're outside [...] and I'm wearing a mask, and there was distance from each other. And I think that created some tension with some of my relatives because they think that I'm overreacting. And so that's what I have to deal with, with my mom and my aunts and me, probably some of my cousins. But I see what they do on social media, you know, like, I see what they're doing. We don't know when our [case] counts are going up. So, I'm cautious," (Participant 068).

"I know that a lot of my friends were not making good decisions at school and not socially distancing, so, for my family and my own safety, I have decided to stay home for the next couple weeks until a vaccine is available."
(Participant 181)

"I feel as though wearing a mask is a challenge. I don't believe it helps, actually makes it worse, and I expect that the government will make us continue to keep them on."
(Participant 234)

Some participants shared that while they engaged in mask-wearing and wanted to promote proper safety behaviors, it took some time for them to become used to the practice. Individuals reported instances in which they would forget to bring a mask with them in public or struggle to keep it on their faces for long periods of time, as the concept of frequent mask-wearing had come with somewhat of a learning curve. Furthermore, various individuals expressed disinterest in wearing a mask due to a medical condition or age. Parents feared that their young children would not be able to tolerate having a mask on their face. Others who either have or know of individuals with developmental disabilities, anxiety, and various conditions, have also indicated concern with the general practice.

"I have a child who can't wear masks. [...] So that affects me as a parent now. How am I supposed to go to work every day, when I have a kid that I come home to that can't wear a mask?"
(Participant 223)

Regardless of opinion, in general, mask-wearing along with physical distancing became components of everyday life. In several places, such practices were mandated by local governments. Various institutions across New Jersey, such as businesses, state offices, and schools, either operated remotely or shut down altogether during the early months of the pandemic. In turn, individuals learned to adapt to a new lifestyle, whether that meant navigating an online world, adopting enhanced safety practices, or doing without certain services all together. *"We were pretty quick to act in March and April [2020], you know, we shut down our schools and we instituted curfews, and sort of limited gatherings and things like that. And I think that was good, because it kind of delayed a lot of the things, and we had a good summer,"* (Participant 213).

"I'm doing a good amount of work from home, just because of what my current situation is. And whenever I used to work from home, I used to go to a coffee shop, and even that I can't do."
(Participant 226)

Some participants chose to isolate because they were immunocompromised or at increased medical risk if they were to contract COVID-19. *"There's really no going out and hanging out. I've pretty much been, like, quarantining because I have a lot of medical issues. So I only go out to go get food, and that's pretty much the extent of it. I don't even get to go see my doctors anymore,"* (Participant 050).

"The biggest challenge I've had is actually not being able to see my grandma. She's in a high-risk category. And for the last couple of months, we just haven't been able to see her. If we do it's with a mask and over six feet apart."
(Participant 412)

As 2020 and the COVID-19 pandemic continued, and holidays and various events approached, many individuals had to find new ways of going about daily life without risking exposure to the virus. Ultimately, many chose to cancel or postpone personal engagements until public health leaders and professionals deemed it safer to do so. Others had modified gatherings that incorporated pandemic health behaviors like wearing masks and physically distancing.

"We're not really having a Thanksgiving dinner because of COVID. My wife and I were going to go out to Thanksgiving at a restaurant in Princeton. [...] We decided to cancel that. Because [...] we're not trying to risk going out in public when we don't have to," (Participant 150).

During this time, individuals began to engage in new, remote behaviors that were once in-person prior to the pandemic. Many reported an increase in online shopping for purchases such as groceries and various home goods, popularizing the rise of curbside pick-up.

"I used to almost always make purchases in-person every month, but now I prefer to make them online, even the purchases for the home, like food for the refrigerator. I no longer go to grocery stores. I simply do it online to avoid the big crowds."
(Participant 075)

Additionally, many individuals engaged in increased sanitation practices to try to prevent the spread of COVID-19. For many it became important to sanitize clothing, groceries, and other various objects before bringing them into their homes. Participants shared that a fear of the unknown about what surfaces may transmit the virus drove this practice, and they worked to prevent the spread through partaking in behaviors recommended to them by public health and medical professionals.

Where information was gathered – about the pandemic and protective health behaviors – varied from person to person. While some individuals relied heavily on the news, some acted based on information gleaned from daily interactions and social media. Many participants placed their trust in national resources such as the CDC for recommendations on how to keep themselves safe. Other individuals had personal conversations with their healthcare providers and other health professionals.

"The CDC has obviously been the number one source that we tried to go to, in the beginning of the pandemic. We – [... and] I think I speak for a lot of medical professionals – were looking to places that were kind of ahead of us in the pandemic, and trying to learn from them, whether it be in management, or therapies, or PPE, [...] as they went through the process, since they seemed to kind of hit the peaks earlier than we did. So, we were relying a lot on publications and things that came out of Europe and Italy and, you know, the UK, since they seemed to be further ahead of us in the pandemic. So those have been kind of the primary sources, and then the main COVID-19 website where they were doing the trackers and things, but honestly, I'm not really looking at that so much anymore. And then, obviously, the hospital websites, and they have been very good about getting us information on a daily or weekly basis about things that are happening in New Jersey and in the hospital as well," (Participant 213).

"My initial source of information was actually one of my family friends. She's an ER nurse at the hospital and was actually assigned to the COVID unit. So all of my information initially came from what she was saying about what they were experiencing in the hospitals."
(Participant 412)

"My main source of information was Dr. Fauci and sort of his advice on what should be done, you know, and how I should make that decision. As far as other sources, I tried to go to the FDA and find out what their recommendations are, I tried to go to the actual published papers to read about the [vaccine] trials or just kind of be informed in a way that is not influenced by politics, maybe a little bit. So I can say that the main news is probably a good source of information for me. I try to go to the original sources," (Participant 425).

Several local resources designed to provide individuals with pandemic-related information were shared by participants as trusted sources. These resources, which were community-based and implemented to address the needs of area residents, provided a more localized approach that participants expressed satisfaction with. *"Well, the program 'Hogares Saludables' ['Healthy Homes'] gives me constant updates on information. Also, from Middlesex County, who sets up the protocol on how to handle the pandemic. And we guide ourselves based on everything that is going on in the entire country. I think that's what has helped me stay updated with everything regarding COVID,"* (Participant 076).

"I use the New Jersey COVID response [website]. I get text messages from them every day. Nj.gov, I have followed very closely what Governor Murphy has been doing. I've listened to him speak, more often than not trying to understand, but I do get a daily update about the resources that I could take advantage of," (Participant 219).

"The Internet is our biggest resource. I found the information on covid19.nj.gov was helpful. Initially, when we're trying to gather information about what's happening in New Jersey, [...] they were good at updating the testing sites and so on, so forth."
(Participant 342)

Information rapidly changed based on new circumstances and findings about COVID-19, and as a result, some participants admitted to being apprehensive of the news they received. This led participants to express concern about the spread of misinformation. Individuals stated that through social media, non-factual information flourished and promoted potentially dangerous ideas and concepts, especially to vulnerable people. Some worked to combat this spread of misinformation by encouraging others to read up on reputable sources for the latest legitimate information about COVID-19.

"I usually try to read multiple points of view, because everybody has their own opinion. And usually, a lot of these in the news networks either lean one way or another. So, I try to get, you know, an idea from each side."
(Participant 408)

"I haven't trusted anything at the beginning because I thought everything was still under investigation. So I just kept it in my head because I can read something today and the next day completely something different comes up. So I tried not to trust anything 100% because everything was under trial and under investigation," (Participant 418).

"I always went to either the CDC website or WHO [World Health Organization]. Obviously, social media has played a huge role. And there would be so many times I see people on Facebook or whatever, you know, saying stuff, and if it was my family, or someone I knew personally, I would encourage them to go to those websites, because everyone would just say their opinion and spread this knowledge. And it was just so frustrating, because [...] no one knows anything, and there's not really any right or wrong answers. So people were just going around saying things and I found myself correcting a lot of people and calling people out on it," (Participant 421).

Other participants expressed that obtaining information about COVID-19 in large quantities at a time brought about various negative mental health outcomes. Participants admitted to refraining from accessing certain sources out of both fear and anxiety.

"In the beginning, it was very overwhelming. Yes, you want to know what's happening and to be aware. But, it's like, when you get up every day and you're just watching the news and listening, and hearing about all the deaths, or about doing this and then tomorrow they change it. [...] You're so stressed and it weighs you down."
(Participant 495)

After the vaccine rollout, everyday life began to shift back from remote to in-person activities for many participants. Entities like businesses and schools had to adapt operating procedures in order to safely and effectively function and reopen during the COVID-19 pandemic.

Furthermore, COVID-19 testing became common practice among individuals and institutions. While some were tested more often than others, many participants shared their experiences. Participants expressed that when testing was performed during the early days of the pandemic, finding availability at a testing site was rather difficult. In some cases, people would wait hours to receive a test, only to not be able to secure one.

"I spent the rest of the day today calling testing centers in my area desperately trying to schedule a test as soon as possible. Unfortunately, almost every testing center was booked until next week."
(Participant 181)

In time, as the number of tests and testing sites increased, accessibility and availability of sites became less of an issue for those wanting to schedule one. A number of local facilities offered free testing to those who indicated interest. One participant shared: *"There is free testing through Rite Aid, but I do know there's more free testing elsewhere, like pop-up locations throughout Newark, so that was a big benefit to me because I got the test not because I felt symptomatic, but because I thought there was an exposure. And then I fortunately took precautions prior to getting my result, and then my result ended up being positive,"* (Participant 002).

"Well, I've been tested several times. And I'm going to continue to get tested and just follow the protocols. I'm wearing a mask and social distancing."
(Participant 044)

In general, as the emergence of COVID-19 brought about unprecedented times, individuals from all walks of life adapted in various ways. While some were impacted more than others, no one was left immune to the new circumstances and protocols. The various COVID-19 health behaviors exhibited by individuals have shifted and evolved since the pandemic's start. As the pandemic is still ongoing, there is still much to learn with the emergence and spread of COVID-19 variants.

Quality of Care

With the increased availability of telemedicine to help avoid contracting the virus from in-person medical appointments, there were varying degrees of the quality of care that individuals received.

Some felt the quality of care provided was excellent in comparison to in-person healthcare because medical services were expedited. There were no extended waiting room times, and some participants felt they received more personalized and thorough attention from doctors.

"Well, I had to do a physical [...] on-site. [...] They would have people scheduled to come in at a particular time. You were socially distant, you had to wear a mask. They kept people apart. And I do remember, if you sat down, you had to wait until it was sanitized. And as soon as you got up and you were called, then someone came along and sanitized. So that was very nice."
(Participant 028)

While telemedicine was successful on many fronts, some individuals did not have the same access to healthcare due to their health insurance, or lack thereof. Many individuals, disproportionately minority populations, lost jobs during the pandemic that had provided them with the health insurance needed for emergencies and regular checkups. Due to this lack of coverage, many individuals were not able to get a COVID-19 test, or cover a hospital stay for their deteriorating health conditions.

"So, we continue to see how the balance is not in our favor, in the favor of our minority groups. Imagine if today is Thursday and today they tell me that my husband has COVID-19, I would have to wait until the next Thursday to get tested. How am I going to be during those six days, emotionally and mentally? How is my whole family, my children, going to be if I do not have the money to take the test and to pay $140? So those are little details, they are things that you say, 'Oh, but they are doing the tests for free.' *Well*

yes, but only on Thursdays? At least make it two days a week. 'Yes, but there are no funds.' *Then we have to ask for funds because these are things that are necessary,"* (Participant 074).

Some individuals with mental health conditions also found telemedicine to be a downgrade from in-person visits. Those who were seeing a psychologist or going to in-person therapy sessions prior to the pandemic sometimes felt they had lost the personalized connection. Many individuals felt as though the online sessions were mundane and less effective, in some cases even causing their mental health to worsen.

"I had to stop therapy and stuff like that, because a call wasn't something that helped me, like, that's not the way that I work, you know, when I function."
(Participant 308)

Yet, many providers pointed out that telemedicine, when appropriate, can be the best use of resources. Not only can it be more efficient, but it eliminates the need for transportation to medical appointments and the burden on the participant to figure out travel. As one participant stated: *"I do know participants miss the connection. But I also know that it was really helpful for many people because Sussex County is such a wide area that transportation and getting the resources we […] provide was hard for a lot of them. So I know that's been a solution for them as well, being able to get our care without having to worry about getting a ride or asking a family member to drive them or finding the one Uber that can bring them during that time. So I know that's been a solution and I think it will continue to be. I think, as a program we'll continue to give the telemedicine as an option because it has helped so many of our participants, and I think moving forward that will continue to be a great thing for them and their time and their resources,"* (Participant 191).

Throughout the pandemic, the quality of care for individuals was largely dependent on their insurance status as well as the health conditions they faced. For some, telemedicine helped expedite processes, while others suffered from the online setting or from not having access to care at all.

Access to Care

Now more than ever, access to care has become an essential concern for people across New Jersey. COVID hospitalizations have strained the capacity and availability of ICU beds, and the supply of COVID-19-related protective equipment and life-saving devices could not meet the demand from providers and patients in need. Particularly in the early days of the pandemic, individuals who wanted to protect themselves and others by getting a COVID-19 test had found it nearly impossible to do so.

Another concern emerged regarding the barriers to accessing care when there were not enough resources available to address a person's medical needs, which came as a surprise to participants. Resulting from a lack of resources, some individuals were not able to receive the proper care that they hoped, or expected, to receive.

"Trying to get a test, just over the river, is really difficult. There are very few places that will do it unless you have a referral from a doctor. And there are a lot of times you want to get tested not because you think you're sick, but because you want to know you're safe to be around someone else."
(Participant 008)

There were instances where individuals with non-COVID-19-related health issues were not able to receive care. One participant shared:

"I start to feel bloated and have a lot of abdominal pain. However no one is seeing me at the moment. My symptoms aren't in correlation to those of COVID-19. I'm told to hold off."
(Participant 501)

Testing and treating the uninsured and underinsured population for COVID-19 also proved a challenge.

"There are still instances occurring where they need a COVID test to enter treatment. And that's really difficult for somebody who is homeless, and unsure of where their belongings are, and how they're going to get to a COVID test."
(Participant 193)

"When my brother was ill with COVID, I took him to the hospital, and because he does not have health insurance, although we arrived first, he was the last to be called. My brother was coughing loudly and another man arrived behind him like 15 minutes later and he was not in much visible pain, but nevertheless when he got to the hospital they asked him if he had health insurance and he said yes so he was allowed to pass first and my brother was left until the end. Then you see those cases and one thinks, help is definitely not the same for everyone, especially for those who don't have health insurance," (Participant 075).

As described in participant accounts, access to COVID-19 resources has been difficult regardless of insurance status. Further, access to care has been especially challenging for those uninsured, and could mean the difference between receiving life-saving care and death.

Maternal and Child Health

New and expecting mothers must navigate many unique, and in many cases, new and stressful experiences, even without a global pandemic. Of those in New Jersey who shared their experience, pregnant people and new parents shared feelings of uncertainty, fear, and isolation as additional stressors that were brought on by COVID-19.

"I found out I was pregnant with our first child at the beginning of February [2020]. […] It is difficult to ignore some of the disappointment and fear around being pregnant during a pandemic. Each doctor appointment brings anxiety about contracting the virus while there. I am worried about losing my job and what that would mean for maternity leave and financially supporting the baby. And the future is still uncertain as to whether my husband will be allowed to be in the delivery room with me when the baby is born," (Participant 059).

Expecting mothers attended doctors' visits and prenatal care alone, creating a sense of isolation and lack of support. Early in the pandemic, birthing parents faced uncertainty about whether they would be allowed to have a support person in the labor and delivery room, or if they would have to wear a mask while giving birth. Even participants who were allowed to have a support person during labor and delivery still felt isolated from additional support from parents, family, and friends.

Furthermore, single parents and those living on low incomes faced greater challenges around childcare, working, and navigating the pandemic while giving birth and attending provider visits. One clinician shared:

> **"Thus, it has been tough for mothers who cannot afford child-care or who do not have family to help with siblings. Their birth partner must leave the night after childbirth to take care of the other children, and the mothers have felt alone during this miraculous and life-changing event."**
> (Participant 334)

Another participant shared fears around protecting themselves and their newborn from COVID-19: *"It's more like not being able to go outside so much with the baby, and stuff like that. It's more the worry, like,* 'Okay, how is–if he should get COVID, how's that gonna impact him?' *Like,* 'How's that going to impact me, the fact that I'm essential? And my job, really, they rely on me to be there at work. Should he be sick, what's gonna happen?' *[...] Testing too. A few of my family members got COVID, and it was like, the worry. Like,* 'Does he have COVID?' *[...] He's coughing, [...] but babies do get congested every now and then. But it's the fact like, okay,* 'Does he have COVID? How do I get him tested for COVID? Or do I just go to a regular COVID site?' *Or it has to be a special place, the fact that he's–he's a baby and whatnot,"* (Participant 256).

Practitioners expressed additional concerns around racial and ethnic disparities in maternal and infant health, and how the pandemic may lead to widened gaps. However, in some communities, pre-pandemic efforts to increase knowledge and awareness around maternal health created strong foundations that have carried throughout the pandemic. *"The racial disparities rising up in this conversation where Black women and women of color did not know that there were doulas in their communities. [...] So being able to do that work pre-pandemic and build that consistency up, we're here to stay. Most times when pilot programs are launched in communities of color, they generally are here and gone. But our goal prior to us becoming a program under Nurture New Jersey was, we were already doing the work as community organizers and doulas, private practice doulas. We were already doing that work. So the program made it–it kind of encompassed it to become more direct and necessary for us to be able to connect with other women and be able to be accessible to women who have a desire to become doulas,"* (Participant 583).

Pregnant people, particularly Black and brown women, have experienced greater difficulties during high-risk pregnancies including clotting issues, diagnosis with other diseases, or mental health concerns. The presence of community resources and better birthing practices, such as doulas, prenatal care, patient advocates, and midwives, have shown to improve birth outcomes for mother and child alike.

Yet, prenatal care was limited throughout the pandemic as resources moved fully online or physicians reduced their hours. As a result, patients were more dependent upon clinicians and clinicians' offices for resources and well-pregnancy visits. One participant shared: *"I didn't really rely much on programs. My OB-GYN, because I was–I stayed in-network, and I've been seeing them for quite some time prior to being pregnant, they were the one who provided me with a lot of packet pamphlets and information to read up on. Unfortunately, at the time, I wanted to do a few of the classes and stuff like that, [...] but they didn't have that due to COVID,"* (Participant 256).

In order to manage some of the stress and fear that came with giving birth during the pandemic, new mothers employed different techniques. Some meditated or did acupuncture, while others focused on keeping themselves and their infants safe through isolation and physical distancing practices. Of the new parents who participated, there was a divide on perspectives related to COVID-19 vaccinations. Some shared concerns about infertility, side effects to babies, and lasting effects on themselves. Others expressed enthusiasm toward being able to transmit antibodies from their vaccination to their children through breastfeeding. Overall, many new and expecting parents found their own way to make the most of bringing a new life into the world during a pandemic.

Social & Economic Factors

Education

"We were connected but through a screen. That was difficult. We lost the sense of togetherness in school."
(Participant 101)

Education was one of the areas most significantly impacted by the COVID-19 pandemic. Parents, children, teachers, and school districts all had to adjust quickly to profound and sudden changes. Major sub-themes that arose included overarching challenges with remote schooling, parents and caregivers taking on the role of teachers, and the digital divide.

Challenges with Remote Schooling/Virtual Learning

The transition to virtual learning at the beginning of the pandemic was a long, unpaved road. There was uncertainty around how long school would stay online, how to teach through a screen, and importantly, how to ensure students were still learning. Schools constantly shifted educational delivery methods, and the changes were sudden and last-minute for many students and teachers, leading to increased stress and frustration. Children's emotional, mental, and physical needs were impacted with the transition to a virtual setting compounded by the loss of in-person socialization. Many participants revealed the issues they faced navigating the remote learning space and the challenges in adapting to a new landscape.

Participants expressed challenges with coursework and learning to use virtual learning platforms and technology (e.g. Google Classroom, WebEx, Zoom). It took time for schools to establish a reliable and effective system and for children to adjust to the transition. In the initial phases of remote learning, many participants revealed the difficulties of engaging and focusing on the computer for prolonged periods of time. While participants shared that teachers and school systems tried to provide support, many felt discouraged to continue their education because of the barriers that online classes or virtual webinars posed. For instance, a participant recalled: *"As a 12 year old, I thought that virtual school was way too long of a screen time for kids my age and even younger. I knew there was nothing we could do about it then, children cannot sit in front of the screen for 6 hours,"* (Participant 315). Students of all grades expressed similar frustrations and sometimes demoralization toward obtaining an education during this time.

Teachers worked throughout the pandemic to continue educating, while navigating the sudden school closures and the transition to remote learning. For many teachers, educators, and school administrators, this was uncharted territory and introduced unique challenges for school staff throughout New Jersey. In a journal chronicling their experiences, one teacher recalled the events leading up to their school's closure

in March 2020: *"Teaching staff is informed to come up with four weeks of instruction should we have to close schools. [...] I tried to help other teachers as best as I could. There were long lines at the copy machine. Staff seemed frustrated and confused,"* (Participant 209). The same participant also described the impact of reopening schools in the fall of 2020: *"Trying to manage online students at the same time as in person students is a two person job. [...] The administration's job is impossible. They effectively listen to the needs of the community and the students. [...] In school we are managing as best we can. There are bad days for sure, and we are working harder than ever."* Another teacher recalled the difficulty of quickly learning and adapting to multiple online learning platforms, all while trying to support parents and students:

"We are informed at a virtual team meeting that we will be able to connect with our students daily. [...] Some words are thrown around the meeting: Zoom, Meet,Loom, Jamboard, Screencast. [...] How am I supposed to teach a group of students – with IEPs no less – on my seven-year-old laptop, using technology I've never been trained in and never even HEARD of!?"
(Participant 204)

Parents and caregivers of children with special needs expressed that there were few opportunities for socialization, and over time children became less engaged. Consequently, there was a loss of academic growth. One participant described the difficulties of using services like speech therapy for their child virtually, stating: *"Because he has a lot of nonverbal communication, sometimes with the questions they ask him, he will just nod and stuff like that. In a classroom […] the teacher could pick up a cue, and the speech pathologist could redirect him right away. But in a computer setting, there's also some lag, so it's very hard for him to engage,"* (Participant 270).

"This online school [is] just not great. Especially for people with learning disabilities or people with IEPs that don't get the help that they need over online [learning]."
(Participant 308)

At the college level, some students described their loss of the "college experience," lacking in-person relationship-building with peers and professors, and having limited ability to seek extra help. Some participants described a decline in academic performance and in some cases nearly failing classes, as the online setting could made completing coursework more difficult. One participant said:

"I was struggling with my virtual classes. Getting adjusted to virtual school was a challenge too. I needed extra help, and I felt like I couldn't get it when I needed it. I almost failed trying to adjust to virtual learning."
(Participant 239)

It was difficult for some students to reach out to teachers with questions or to ask for help, and participants described experiencing a decline in their focus and attention spans as virtual classes continued. Many felt the virtual setting was not conducive to a group dynamic, with the opportunity to exchange ideas face-to-face largely reduced. Participants in health professional schools and programs discussed the challenges of losing essential in-person training, where they could practice skills for real-world settings. One nursing student shared:

"I can't help but feel nervous for the future. How will I assess a real live human being in a few weeks when I've only practiced on video calls?"
(Participant 181)

"Something I really learned, especially after COVID, is that in order to learn or be motivated to learn, you need human interaction. And I remember there were times I would go to a lecture, but I didn't exactly pay attention all the time. But I still, at the end of the day, felt like I was learning because being in that environment, watching other students take notes, just watching a teacher speak to me in-person, just motivated me," (Participant 071).

Parents/Caregivers Functioning as Teachers

In March 2020, many parents and caregivers found themselves taking on roles as teachers at home when most New Jersey K-12 schools abruptly transitioned to remote learning. The challenges of balancing daily life alongside the responsibilities of teaching were mentioned often, as many parents and caregivers already busy with work now had the added responsibility of supervising their children at home for school. Parents who previously relied on community programs or organizations to help their children with homework faced significant challenges in accessing such services with many programs shut down. The need to balance multiple and additional responsibilities, such as monitoring their children's school schedules while taking care of younger children, and working or looking for work, was emotionally taxing for many. One participant shared:

"Previously, my job was always busy. But there was a clear divide between home life and working. Now, it feels like I am working every hour that I'm not sleeping for 13 months at this point, and, you know, it's been hard on my family. It's been hard on me, specifically because there really isn't time to decompress."
(Participant 555)

Participants described varying levels of preparedness from schools in their responses for the switch to virtual learning. One individual saw a decrease in the level of homework provided, and resorted to creating their own homework for their child, sharing that their student was assigned videos to watch without virtual meetings or live instruction. On the other hand, some participants explained that their schools provided a lot of work with little interaction. This was difficult for many students who required additional support with schoolwork. Parents and caregivers expressed that having their children sit in front of the computer for prolonged hours was not constructive nor ideal, with some choosing to homeschool instead. One participant shared: *"We homeschool instead of virtual [school] because there was no way we could do virtual. She would have not sat in front of the computer for five hours. [...] And it's still a struggle because she doesn't–she'd rather be doing what my four-year-old's doing and play,"* (Participant 115).

As participants realized that their roles as parents and caregivers had evolved to include educator, many shared how ill-equipped they felt. One participant explained: *"Families have struggled with behavioral issues, academic progression has been a big one. Because parents don't know how to teach their kid multiplication, or long division, or whatever. Oh, I mean, we tried to do it the way we all learned it, like 1,000 years ago, but that's not even the way now. And [...] a lot of like, interpersonal relationships start to get strained. Because you have to be the mom and the teacher and the disciplinarian and the speech therapist and the life coach, and somehow [...] keep your job during all of that,"* (Participant 277).

"The way that these kids are learning material is not the same as how I learned it. So, we had some complications trying to decipher exactly the task at hand."
(Participant 502)

Parents and caregivers also found themselves suddenly becoming the main social interaction for their children. For instance, with sports and other activities canceled or largely reduced, it was up to parents and caregivers to entertain their children at home. Families navigated different ways of adapting to virtual or hybrid learning, while creating spaces for children to work and play.

However, motivation dwindled for both caregivers and children as the pandemic continued. One parent shared their frustration, and expressed that they had been forcing their child to attend school and eventually felt they had to give up. It became more difficult to keep logging on, and the parent could

not take on the job of a teacher while also working from home. Parents and caregivers tried to increase engagement in virtual learning for their children by incorporating activities like yoga, video calls with friends, decorating the learning space at home, and even taking pictures on their first day of virtual school. Yet, as parents and caregivers adjusted to these new responsibilities at home, and children faced the loss of social interactions at school and after-school activities, the adaptation to virtual learning introduced a unique and wide-reaching set of challenges for New Jersey families.

"I've been here with them, I've been able to just kind of monitor, make sure they're keeping up and that they're engaged, and just making sure they are okay. You know, making sure they're handling everything and answering their questions and that kind of thing."
(Participant 407)

Digital Divide

The increased use of digital devices during the COVID-19 pandemic affected workspaces, schooling, and standard communication methods. This has highlighted both inequitable access to, and familiarity with, technology, contributing to a growing digital divide. Participants explained having to use various devices simultaneously – switching from laptops to phones and vice versa – while navigating new applications and online tools. The introduction of technology for virtual learning was a new, and in many cases, difficult transition for both educators and students. Participants mentioned that with multiple people working, learning, and doing other virtual activities from home, Wi-Fi bandwidth limitations often led to connection issues. One participant said: *"Definitely with bandwidth, my dad is a college professor as well. And well, he's trying to teach [...] like 30 kids in the class, and I'm in a class with 30 kids. So on those days [...] we know that things might be running slower. He's had to restart meetings before. And it's just certain areas of the house where there's like a dead spot in Wi-Fi. So luckily, I have a good connection in my room, but in various parts like the living room where he should be doing his work, it goes in and out. So, he has to go to the dining room. Oh, and especially with the snowstorms lately, that was a big problem with technology, any big storms. If the power went out or anything, you can't go to class, and I know that some professors had to cancel,"* (Participant 366).

Difficulties and unpredictability in internet access and connection were especially detrimental to virtual learning, particularly in the early stages of the pandemic. One participant said: *"In school life, it has also affected me a little bit because of communication limitations. For example, with the internet. Problems with the internet that a lot of students have had, with connection. [...] My kid was not able to get classes for about a week. Then I spoke with his teachers, and they accommodated me. They gave him some extra work that covered what he had missed from that whole week of classes. They tried to help me catch up with everything he had missed,"* (Participant 075).

Wi-Fi and internet bandwidth are only a couple of aspects to the multifaceted challenges of the digital divide. Some participants shared that they did not have access to technology or lived in a community with no internet hotspots. In some cases, participants were forced to spend their savings on buying a computer or installing internet. Some participants mentioned that they had outdated laptops, which caused missed classes and assignments due to lack of capability to work with more recent software or applications.

"So you know, I'm afraid. Kids [...] are getting left behind because they don't have [...] access to the appropriate technology to engage in school learning."
(Participant 150)

Programs like Internet Essentials from Comcast, and other low-cost broadband adoption programs, supported access for some families, but they often provided only very low bandwidth. This created issues when families tried to connect more than one device simultaneously. Furthermore, while many school districts provided their students with technology such as Chromebooks, the need has far outweighed the supply in many areas across New Jersey.

Beyond virtual learning and working, the lack of access to technology also affected those trying to register for vaccines, unemployment, Supplemental Assistance Nutrition Program (SNAP) benefits, and even court appearances throughout the pandemic. Some people struggled with having enough minutes or data on their phones, and even if they had a device, Wi-Fi may have not been accessible. In rural areas of the state, a limited number of services and resources compounded this lack of access to technology. As one participant shared: *"An essential means for Salem County is a car, anything transportation-wise, and not all residents can afford even a vehicle. So, it's like, if you didn't have a good Wi-Fi connection, and you didn't have a vehicle – which a lot of Salem residents can't or aren't able to have – you really didn't have a large resource to pull from for help in this time,"* (Participant 475).

Many older adults, often a population most at-risk for social isolation, did not have access to or familiarity with technology during this time. Coffee shops or libraries, where older adults had frequented before for Wi-Fi or computer access, were closed during the pandemic, leaving many without ways to communicate with their families, keep up with current events, or find testing or vaccination sites. This technological divide led local organizations and programs to develop strategies aimed at bridging the digital gap:

"So as a result, we have joined the National Digital Inclusion Alliance, that is fighting for equality for everybody, not just seniors. But, seniors seem to be the population that needs the most help and most attention."
(Participant 026)

One program at a local nonprofit connected high school students with older adults in their community to teach them how to navigate technology, assisting them in connecting with their families virtually.

Moreover, with many daily activities and resources moving online, English became the primary language for instruction, and many families experienced difficulties due to a language barrier. With all or most schoolwork provided only in English, it became complicated for some parents or caregivers who did not speak English to understand and help their children. One participant mentioned: *"There was an evident challenge with technology and learning how to use various platforms for the children's schooling. In addition to this, almost everything was in English, which made it harder for those who do not speak the language,"* (Participant 572).

Likewise, scheduling testing and vaccine appointments also introduced language barriers. Many websites with information and resources for testing or vaccination were not offered in multiple languages, restricting non-English speakers from scheduling appointments. One participant recalled: *"I am the one who scheduled my dad for the vaccine because he wouldn't be able to do it on his own on the computer schedule because he's–we're Haitian. [...] My mother and father, they were born in Haiti. So, I'm like the first-generation Haitian-American. Certain things I have to do for them, especially on the computer. So, I signed him up for the vaccine, my sister signed up my mother for the vaccine,"* (Participant 514).

Artwork by Participant 186

"A Series of Unfortunate Events"

A series of unfortunate events (not written by Lemony Snicket): due to COVID-19, I lost my apartment, because I lost my job (that allowed me to pay my bills). When I lost my apartment I became homeless, when the Covenant House of Atlantic City, NJ, took me in.

Physical Environment

The safety guidelines implemented during the COVID-19 pandemic focused on physical distancing and quarantining in order to prevent community spread of the virus. As a result, people had to adapt to new living arrangements and modified routines, while also navigating the pre-existing limitations of their spaces. Violence, homelessness, housing and food insecurity, lack of transportation, and access to healthcare were all issues within people's physical environments that long predated COVID-19, but were amplified due to the pandemic. Amidst these challenges in adapting to their shifting environments, participants also faced a decrease in standard resources, financial or economic instability, and the loss of in-person connections.

Families' daily routines changed to accommodate new activities such as teleworking and virtual schooling, adding pressure to already limited time and space. People carved places to work out of their living spaces, or adapted to transitional situations. One participant described living in a hotel room with their family while waiting for their new apartment:

> **"It's still four people on top of each other and we still gotta do remote learning. [...] But the whole time I'm like, I got to deal with insurance, then with the landlord, then still doing my organization, still making sure they got school going on."**
> (Participant 020)

With many activities being constrained to the home, multiple participants also noted a decrease in opportunities for physical activity. The loss of routine that had previously allowed for more movement, such as commuting, going to the gym, or driving children to various activities, was now spent looking for ways to keep entertained indoors, or through limited and physically-distanced activities outdoors.

Confinement to the home also resulted in social and health concerns for families quarantining together. The lack of public activities like school, organized sports, and movies resulted in reduced opportunities for socialization. Some participants chose to stay with relatives, relying on the comfort of being with family. One participant described having rotating arrangements to stay with different family members, essentially traveling across the state and *"living out of suitcases,"* (Participant 083). Family members who congregated within one household to escape isolation also faced new concerns around the possibility of exposure to COVID-19. This was particularly worrisome for families in small living spaces, as one participant explained: *"We have heard of impoverished families living in close quarters, ultimately unable to protect their loved ones from COVID-19, after bringing the disease home from a job they could not afford to lose or walk away from,"* (Participant 335). This concern also presented a barrier for individuals searching for a job, as another participant pointed out:

"Because my mother is at high risk, and I stay with her, I can't take a job like in Home Depot, or, you know [...] out there in the public. [...] I've got to do a job where I work from home, and that's challenging too."
(Participant 161)

There were some environments where social distancing was impossible, putting many populations already experiencing vulnerability further at risk for contracting COVID-19. Correctional facilities, shelters, and other places of crowded living were less equipped to stop the spread of the virus if one person fell ill. Additionally, long-term care facilities and group homes for older adults or individuals with disabilities had to enforce strict visitation rules, which kept families apart for extended periods of time. Multiple participants with family members living in group homes spoke about the struggles of protecting the safety of their loved ones without compromising their treatment and overall well-being. For many, the pandemic also halted progress toward independent living, changing previously stable and supportive physical environments and exacerbating challenges of already complex or limited spaces. One participant, who shared about the changed living environment for their child, stated: *"Prior to the pandemic, my oldest son was living in his transition, [...] a supported independent living program. [...] So that was going pretty well, for a year and a half. And then the pandemic came, and he came back home to live with us,"* (Participant 267).

Housing

Many participants experienced shifts in their living situations and housing stability. Prospective home buyers and college students had to find alternative living arrangements when the pandemic hit. One participant shared that they had been *"in the middle of the process of buying a home. [...] Unfortunately, the person that was selling our home, coming to find out when he was tested for COVID, he was deported,"* (Participant 036). This led to them losing the contract on their prospective new home, and rushing a lease for a rental property which exceeded their intended budget.

For the housing-insecure population, and individuals experiencing homelessness, challenges and concerns heightened during the pandemic. One participant spoke of friends who had been illegally evicted from their homes by their landlords, suggesting that even policy measures put in place to preserve housing have failed to protect people at times.

Not only did many face the loss of their homes during the COVID-19 pandemic, but unhoused populations already navigating the challenges of homelessness saw their options for housing dwindling. Some faced difficulties in applying for housing due to documentation barriers or procedures. Individuals who relied on public indoor businesses for heat and shelter during store hours no longer had access to the temporary relief:

"Most of the stores are closed down. I rely on stores like Walmart for heat and to occupy my day, to find shelter that will help you feel safe and secure."
(Participant 238)

Yet, shelters are not always an option or all-encompassing solution, as one participant noted: *"Unfortunately, the majority of the homeless population has some type of complaint or resentment toward their shelter placement. [...] They've had bad experiences there, and they don't wish to go there, so that's the challenge,"* (Participant 201). This sentiment was supported by accounts from participants who expressed reluctance to go into shelters due to negative past experiences and anticipation of conflict with other occupants.

Content note: The following quote contains language with some profanity.

Moreover, finding temporary housing could be a complicated and frustrating process. As explained by a participant, who shared that they experienced homelessness for the first time during the pandemic: *"Most of the spots, all they do is give you the run-around. […] They send you on a rabbit chase a lot.* 'Go here,' *they can't help you.* 'Go to this spot,' *they can't help you. It's just a whole lot of time. You look at what you're doing, it's a fuckin' waste of time. You can actually do something more productive than just running around. So that's what I mean by* 'the system is fucked up.' *You just do a whole bunch of running around. Nothing is accomplished, and then by the time you notice, fuckin' four months has passed by,"* (Participant 197). Finding or maintaining safe, stable, and supportive living arrangements during the pandemic was a challenge shared by many New Jersey participants, as individuals sought to keep themselves and family members safe from COVID-19 while navigating the adverse impacts on current and prospective housing situations.

Transportation Impacts

For those who relied on public transportation, COVID-19 presented an additional set of challenges. With reduced transportation, many people were unable to access their employment locations, schools, healthcare, or food. Several participants discussed the impact of reduced transportation on their ability to find and maintain employment. Some participants noted that even though there were job openings at local retail stores and groceries, they were discouraged to apply because they did not have a reliable means to get there. Additionally, even when transportation was available, people expressed concern over potential exposure to COVID-19 from riding trains or buses to work, appointments, and errands.

"We've noticed that transportation has become a severe issue with COVID. A lot of our families depend on public transportation, and being around other people while they are getting from their home to a grocery store."
(Participant 058)

One participant noted that a sufficient transportation infrastructure has long been lacking across rural areas in the state, making access to private vehicles a necessity even before the pandemic, stating: *"Families in our rural areas are more difficult to reach, they are vulnerable to missing important and timely information, [...] there are limited services in place to connect them to, and what services do exist can often be too long-distance for them to access,"* (Participant 335).

Healthcare Impacts Due to Transportation Barriers

Healthcare was also impacted by reduced and insufficient transportation, during a time when it was most critical. One participant noted their difficulty with maintaining ongoing care because they could not make it to their doctor appointments, sharing: *"I have some medical problems but that is hard to take care of when you cannot see someone or have transportation,"* (Participant 232). Organizations reported identifying these concerns and addressing them through grants to provide more transportation options. At times, providers offered rides themselves or handed out bus cards to patients and families. These supports were limited, especially as the pandemic stretched on. When it came to finding testing centers, the limited hours and locations made it difficult for those without private transportation:

> **"For example, a county [testing center] that is only open on Thursdays like here in New Brunswick, that person who has a car can go to Piscataway on Mondays or Tuesdays when they open there. We have to focus on the people who cannot pay for a taxi to Piscataway or they cannot pay for a test here. They need those tests to be reassured, to be safe."**
> (Participant 074)

Health services and access to such services, intertwined with adequate access to transportation, are just a few of the many social and economic issues exacerbated by COVID-19.

Access to Food

Barriers to food access also presented heightened challenges during the pandemic, as food insecurity increased across New Jersey. Beyond existing barriers in access to fresh and nutritious food, the rush to stock up on supplies left shelves empty before they could be restocked, particularly in the early months of the pandemic. Participants described this shortage of essential products at their local stores: *"Definitely not like a normal day where you can just go to the store and get something you need. Everything's like, off the shelves. [...] That was the greatest disappointment, because the kids are home more, so they have to eat more. So we're running to the store more, and there's just nothing there,"* (Participant 080).

Facing a reduction of supplies within walking distance, financial difficulties, and fear of exposure, many turned to food drives and meals offered by churches, schools, food pantries, and local organizations.

Several participants expressed gratitude for the food, particularly fresh produce, that was made available through these distribution sites:

"The main thing that I received was definitely food. [...] I found there were definitely so many resources that were just giving food, and they made it so easy. You just had to pull up, or even some people delivered it to my house. So that was a mercy."
(Participants 164)

Participants also praised outreach efforts on social media, such as promotion and reminders about local food distributions. Even with the additional food providers, securing adequate transportation proved an issue. Some individuals could not make it regularly to distribution locations, or were concerned about having to walk back home carrying heavy grocery bags. One participant suggested that it would have been more beneficial to provide money for food directly or expand pandemic EBT cards, and shared: *"I know some local schools were offering [...] breakfast, lunch, and dinner. But that in itself was hard because, you know, if a parent is trying to find work, are you really gonna send your eight-year-old to pick up their lunch, or their meals from school?"* (Participant 069).

Several participants noted that, in these cases, it was other community members who stepped up and offered to deliver groceries for their neighbors. This assistance came not only from individuals with cars and easier mobility, but also from people who valued these resources from their own experiences and needs. For instance, one participant shared: *"My greatest disappointment happened when the Trenton Area Soup Kitchen (TASK) closed due to COVID. This is where my hot meals came from. When things get better, I would like to volunteer there,"* (Participant 099). Other participants noted that when the food and clothing drives offered a surplus of items, it was easy to share with neighbors who could not get to the locations themselves: *"Wherever we go we try to help others. […] You get a blessing by what you doin', helpin' others! [...] I get more joy outta just walkin' and helpin' people. […] I'm homeless too! But I still help the homeless, you know? [...] Whenever they give out free stuff, I go and get extra stuff to give out [to] people I know that can't walk, or got one leg, or […] can't hear, whatever. I know they in a place where they can't get to the clothes. I'll get it and I'll go give it to them,"* (Participant 200).

Economic Factors

"In the past, low-income families may have been able to sustain a single unexpected blow such as an illness or a broken down car – in the pandemic environment, these events are now catastrophic. [...] There are formerly moderate income families who are now sliding into poverty for the first time as well."
(Participant 335)

Employment

The impact on New Jersey's employment landscape was a polarized topic throughout the pandemic. Some individuals described upticks in their work, working more hours and on busier schedules, while others experienced a reduction in their work hours or loss of employment. Participants working through the pandemic expressed their fears about keeping safe while needing to work, and the uncertainty surrounding their health. For instance, participants who worked in healthcare settings often shared about their constant contact with other people, bringing their work stress home with them, and dwelling in negative thoughts during this time. Continuing to go out to work was a tough decision for many people, and for some participants, it became distressing to go to work and have to isolate or quarantine from family members for weeks and months. One participant shared: *"When the pandemic happened, I felt like our superiors [...] kind of brushed it off, as in* 'Oh, you guys can't wear a mask,' *because they didn't want to scare the customer. [...] It was scary in that sense, because I was an essential worker working in a supermarket,"* (Participant 514).

Eventually, while businesses transitioned to wearing gloves and masks, as well as adopted increased safety protocols, the adjustments and changes in the workplace created troubling emotions and anxiety for employees. Some participants explained that they felt there was no choice but to go to work. Workers from low-income households in essential positions were less enabled to protect themselves and their loved ones from COVID-19, often because they could not afford to leave or take time off from their jobs and risk losing income.

Yet, for many participants, particularly those working in healthcare settings, the workload increased dramatically during the pandemic.

"To say I now have my hands full would be an understatement."
(Participant 449)

Participants mentioned transitioning into working more days or longer hours each week, even managing multiple new roles, responsibilities, or shifts to support their workplace. Many in healthcare and public service viewed their jobs as an obligation, even as their work increased or became more hectic as the pandemic progressed.

Some participants' employers allowed them to work from home, yet this presented its own challenges for individuals in managing and juggling their responsibilities and productivity. For many participants working remotely, the loss of communication and interaction with coworkers also led to difficulties maintaining or building personal connections in the workplace.

"When you're in-person, even at work you get breaks. You get to walk to fill up your water, or you get to [...] stop by somebody's desk and talk to them. And you get to just have that in-person connection. And those little moments throughout your day, where you're like, 'Oh, man, I just had a really heavy project to get done. But I got to pass by Susie's cube and talk to her,' *it brightened your day in that moment,"* (Participant 475).

Childcare Arrangements

Participants who are parents or caregivers shared about the difficult changes and battling priorities faced daily during the COVID-19 pandemic. With many childcare centers closed or operating on changed schedules, parents and caregivers navigated working full days at home or at their workplaces, while supporting and assisting their children with virtual school and activities. It was tough for some parents to continue to work at their current job, or find a job that fit their new schedules. Shared one parent: *"My life has become busier since the pandemic while working. I work, and I'm working virtually. And also, I'm homeschooling. During the pandemic, there was very little outside activities, which meant I was stuck in a house with children, and no time, no money. So, my life was tremendously changed,"* (Participant 077).

Many times childcare became a joint effort between parents and family members. According to one participant, *"My husband and I […] really had to take turns. I needed to know when he had business phone calls. I was available to supervise my son, because my son would barge in on any business video. And while I was trying to continue to work, I also would need him to cover so that I could have a business phone call,"* (Participant 267). Finding the time and space to work became difficult for many, and opting for a nanny or babysitter services could be expensive or deemed unsafe by parents. One participant said:

"Childcare is an absolute nightmare. Every day, my husband and I scramble to find someone to watch our two children. Then the fun really begins when I try to explain their virtual schedule."
(Participant 204)

Parents and caregivers, especially those working in essential industries, found it difficult to juggle their work responsibilities while securing childcare. This challenge was compounded by the fear of bringing COVID-19 home, despite undertaking safety precautions. This intensive schedule and constant fear took a physical and emotional toll on many participants, as some explained experiencing negative impacts on their sleep, being unable to take days off to relax or unwind, and feeling stuck in a "loop" day-in and day-out.

Some participants explained their difficult decisions to leave their jobs during the pandemic in order to be a more present caretaker at home. One participant shared:

"[Working] lasted to about August, when I could no longer divide my time. I couldn't give 100% to either situation, so I resigned from my job to stay home. So, you know, to attend to my kids."
(Participant 275)

With changing lifestyles at home, work, and school, some participants acutely felt the added pressures of being their children's primary caretaker throughout the day. One participant likened it to their cup overflowing: *"This is yet one more thing that you have to add to my schedule. [...] My cup is full. So, I think a small drop just sends me over the limit at this point, of course, and my reaction could be sometimes disproportionate to what I've been asked,"* (Participant 271).

Within the breadth of unique choices and changes families faced during the pandemic, decisions between work, school, family, and health remained immensely challenging and impactful.

Loss of Jobs & Business

With the pandemic's economic toll on New Jersey, many participants were forced to navigate loss of employment and their relied-upon sources of income. Every level of the economy, from state budgets to personal finances, was significantly impacted, affecting individuals' welfare as well as their physical and mental well-being. The feeling of constant uncertainty for those who lost employment was shared frequently, as participants expressed concern about when they would be able to return to work, or how long it would take to find new employment. Shared one participant:

"I've lost my job, and have gained a different position, but it's not quite as good as before. My fiancé lost his job. He worked in a restaurant, and it's been complicated for him to find a new job. So, it's just been rough."
(Participant 552)

Some participants explained that they were working in the beginning of the pandemic, but later were laid off from their positions. Other participants took on second or third jobs to create additional streams of income, and many went on to find completely new lines of work. Those who were fortunate enough to retain their jobs faced reduced hours in many cases, and struggled to find additional hours or pick up shifts to make up for the resulting loss in income.

"I got laid off from my job. I was very upset because my unemployment wasn't coming through and I had no way to pay for my expenses and things I needed. Then, when I got called back into work, they reduced hours and that wasn't much of a help either. That resulted in me having to get a second job."
(Participant 463)

A recurring concern of not knowing where the next paycheck would come from, or even if it would be enough to cover expenses, only added to the existing economic pressures of the pandemic.

Financial/Economic Instability & Inability to Meet Basic Needs

The economic upheaval, particularly from the loss of jobs during the COVID-19 pandemic, had devastating effects on New Jersey residents' financial stress. The loss or reduction of paychecks impacted housing and food security, negatively affected mental health, and created additional financial limitations.

Participants chronicled their experiences of spending entire saving accounts, taking out loans, and accumulating negative account balances to make ends meet. Shared one participant: *"I'm about $18,000 in debt, with my pension, and it's gonna take me about three years to pay it off, to even get back up to my regular paycheck standards. [...] What people don't understand in the government and with a lot of these programs, is that they still base it on your gross, when in actuality your net is far below that poverty line. And it's really putting people in danger, from having to take out so many loans and everything, and then having to pay them back at such higher interest rates and everything. That is putting people in danger of losing their homes, having their electric possibly shut off, the water shut off, not being able to provide food for their families,"* (Participant 036).

Participants who lost their employment, particularly in the service industries, commented on the challenges of businesses shutting down and the subsequent long wait times for obtaining unemployment benefits. Furthermore, many were not aware of what benefits they could apply for, or be eligible to receive. One participant shared: *"I got laid off from my job, and it hasn't been good. All of my bills have been backed up. I'm struggling. I don't qualify for anything, and it's sad, because you would think a working person would qualify for something, and I don't. So I'm working off a bare minimum. [...] Keeping this roof over my head, the rent, the lights, even though they extended it, the bills are only jumping. So,*

it's affordability. I can't afford anything at this moment. Like, it's really hard. [...] Right now, the only thing I do receive is food stamps. That's the only thing that I qualify for," (Participant 051).

Financial assistance provided through Economic Impact Payments, known as federal stimulus checks, offered temporary relief for some. *"I tried to apply for the unemployment, they denied me [...] because I was still working part time. [...] That made me really upset, because I really need it. I needed the extra money to cover my bills, because I'm a single mom. Thank God they gave the stimulus, and they helped me,"* (Participant 116). Another participant shared: *"I think through this pandemic, for the number of people that have lost their jobs, the relief that has come from the federal government has been life-saving,"* (Participant 584).

Still, for many, this assistance did not nearly meet the financial need exacerbated by the pandemic, particularly in covering basic and household expenses. One participant shared:

"I don't know who's gonna get it. And I just feel bad that, for the people that really need the money, $600 is a joke. You know, I mean, they should do a better job, they had nine months to figure out how to means test it."
(Participant 268)

This economic uncertainty pushed many families to the brink of extreme financial hardship, and also exacerbated disparities in wealth by race and ethnicity. As one participant noted:

"The numbers show very clearly that Black and brown communities were not treated equally during COVID. They [...] don't have the kind of savings and kind of generational wealth that has been handed down to people that are white and people that are of privilege."
(Participant 218)

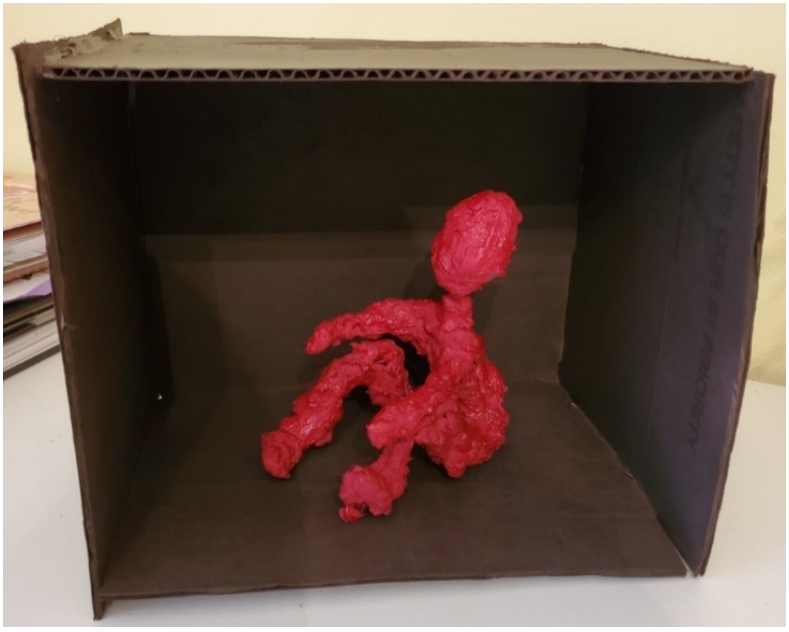
Without generational wealth or savings, many participants described their greatest challenge during this time as the lack of income to cover rent and utilities. For many, this resulted in increased housing insecurity or the loss of their home: *"As a result of the pandemic, I've ended up homeless. I've been laid off from work, and any job I have gotten, the hours have been drastically cut. [...] My electricity and gas had been cut off, so I would say that taking cold showers and not being able to cook food took a toll on me. Not having any money also was one of my biggest challenges, because I wasn't able to buy myself toiletries or food, or anything I've needed in general,"* (Participant 261).

Others found themselves choosing between buying food or buying personal protective equipment. Many participants felt unsure whether their paycheck could cover hand sanitizer and gloves to prevent the spread of germs, a computer and internet to work and learn from home, or routine medical care or tests. Some even considered selling off all furniture to pay their bills.

One participant described panhandling during the pandemic, just to earn money for daily necessities like food: *"To be able to buy my wife and I something to eat. We get a cup of coffee or something like that. And sometimes it can be embarrassing, ya know. People will laugh at us, they make fun of us,* 'Look at this guy out here beggin' for money.' *[...] They give out whatever change they have, like they'll give a dollar here and there. [...] It's enough that it gets us a sandwich or something,"* (Participant 199).

Many participants shared that the economic hardships they faced led to a decline in their mental health and well-being. *"I worry,* 'How am I supposed to pay school tuition? How am I supposed to pay a car bill or anything like that?' *So, I think money has been the biggest issue for me and my parents,"* (Participant 417). The combined stress of losing a job, paying bills, accumulating debt, and feeling discouraged in finding new work often contributed to feelings of hopelessness. As one participant shared: *"[The hardest part was] losing my job because of COVID-19. And the stress of not having any income for over seven months, with bills still coming in. My anxiety was definitely on high,"* (Participant 161).

The stress and uncertainty caused or heightened by the pandemic snowballed as more industries were hit and more people were affected. Mental health, already a topic on the rise, stood front and center as people tried to cope with the unprecedented times.



Artwork by Participant 292

"Helpless Isolation"

Wire, CelluClay, Cardboard and Spray Paint

1/15/2021-1/25/2021

My art piece shows my feelings of being isolated from society and the outside world. My piece also represents my hopelessness in trying to change how I feel. I believe that many kids have been affected negatively by having to quarantine and isolate from other kids and family. I hope that my simple piece can visually show people how it feels to be a kid during this pandemic, where everything we have known and experienced our whole lives has changed.

Mental Health

**"You're trying to protect yourself from a virus,
but mentally you're messing up [your] mental health."**
(Participant 418)

"The COVID-19 pandemic has had a major effect on our lives, and many of us are facing challenges that can be stressful, overwhelming, and cause strong emotions in adults and children. [….] So it's important that we look after our mental health, as well as our physical health. […] They would never tell someone with a broken leg that they should stop wallowing and get it together. We don't consider taking medication for an ear infection something to be ashamed of. We shouldn't treat mental health conditions any differently. Instead, we should make it clear that getting help isn't a sign of weakness. It's a sign of strength, and we should ensure that people can get the treatment they need," (Participant 333).

"My greatest fear is catching COVID-19 and bringing it home to my family."
(Participant 233)

The COVID-19 pandemic and changes in social, economic, and physical environments has taken a toll on mental health for individuals across New Jersey. Participants shared about the negative impacts they experienced, and barriers that increased for individuals already living with mental health issues. Yet, many participants discussed areas where they found positive outlooks and impacts, support, and resilience.

Many individuals were separated from their loved ones and their networks of support when quarantines were instituted, stemming from the early months of the pandemic into 2021. Not knowing when the pandemic would end and when they could be reunited with family and friends, many found themselves confronting new or existing challenges regarding their mental health and emotional well-being. Participants cited these constant changes and uncertainty as adding to their overall stress.

"We can't make plans for tomorrow because tomorrow things will change completely. [...] Sometimes, well, for me that is a huge obstacle because [...] I can't plan for the next day. Day by day things are changing. The job losses, the utility debts that a lot of people are talking about, the return to schools, not knowing exactly how to handle this situation, it's all really stressful and they are some of the most difficult obstacles that we could be experiencing right now," (Participant 074).

Beyond adapting to and overcoming unanticipated impacts on daily life, participants found it difficult to keep up with frequently changing and updating guidelines or safety protocols.

"Being careful about every little thing you do is hard. Knowing I can endanger my family is hard, so it makes me follow the guidelines so I do not put anyone in danger."
(Participant 237)

The persistent stress, grief, fear, and uncertainty created by the pandemic has impacted adults around the world, but studies are increasingly focusing on the effect on children. According to the Journal of the American Medical Association (JAMA) and studies from multiple universities around the country, approximately 40,000 children lost a parent to COVID-19 in the United States (Kidman et al., 2021). In New Jersey, "there is no official count of how many victims had young children," (Clark, 2021).

At some level, most children experienced the loss of financial stability, shifts in education and learning, changes to healthcare, and impacts within community systems of support. Furthermore, children, particularly of Asian descent, personally experienced or indirectly viewed increased racism and xenophobia during the pandemic[6] (Donaghue, 2021). Even as the world begins to emerge on the other side of the pandemic with the development of vaccines and innovative treatments for COVID-19, the stress and trauma endured will continue to have a lasting impact on children and teenagers.

In this "new normal," parents and caregivers have looked for ways to offer their children options for socialization and improving mental health. Yet, participant concerns about the risks of contracting or spreading COVID-19, particularly when vaccines had not yet been approved for children ages 17 and under, remained. *"I saw that not being around the kids has affected him so much as far as, I would say, emotional, mental, and physical well-being, and overall well-being, we'll say. But even that, it's so difficult because you know, the risk. It's still a big risk, but at the same time, it's been so many months, the kids have to have some kind of socialization. And so I have to trust that, just like the camp put strict protocols in place, that the schools will also put protocols and everybody's safety and well-being in place, and do their best to keep everyone safe,"* (Participant 018).

Witnessing the far reaching impacts of the pandemic on mental and emotional well-being, the pandemic has fostered new proponents and amplified the work of existing mental health advocates within many New Jersey communities. Participants spoke to the need for empathy and compassion, as well as keeping lines of communication open for those needing support.

6 FBI report that highlighted that hate crimes were at their highest in 2020 (since 2008).

"And that's why this is so important, to build bridges to each other so that we can keep a level of sanity."
(Participant 020)

Furthermore, participants touched on the importance and critical nature of individualized approaches to mental health supports. *"It's during all this I feel like adults can really help by talking to teenagers and see how they're coping, and really get a better insight of how teenagers feel about everything. Because there's no two teenagers that think the same way. You can ask one teenager how they're coping and it'll be completely different compared to how other teenagers are coping. So [...] creating an open space where teenagers can feel free to talk about what's going on and be able to provide different opportunities to cope with everything will be very beneficial,"* (Participant 025).

"We know that you cannot go in person often to ask for help, but sometimes even calls are not answered. [...] So, right now we need a lot of empathy and a lot of human warmth."
(Participant 074)

Challenges and Lack of Resources

While mental health was a frequently recurring theme, many participants shared that they faced a dearth of resources for support. The supply of mental health providers was not enough to meet the overwhelming need from those seeking services and assistance. A study published in *Psychiatric Services* found that more than 25% of American adults who had symptoms of depression or anxiety reported an unmet need for mental health counseling at the end of 2020 (Nagata et al., 2021).

"We really have not addressed mental health at all, anywhere, and the mental health and well-being of our little ones, and our medium-sized ones. At least for those of us who are a little older, we have experiences with certain things like tragedies, or crisis, or trauma. But there is not anything by the stretch of an imagination that we're even doing now today when we all know and see the repercussions of the mental health crisis going on during COVID. And still [...] there's not really much anybody can offer anybody in way of resources, or counseling. [...] A lot of us are really doing our best, but I mean, higher up, it's just tragic. The mental health issues are going follow us for decades," (Participant 126).

Several participants cited a need to bolster mental health resources not only during the pandemic, but well into the future. *"Getting more on board with the mental health, [...] we're going to see such an increase in mental illness as the long-term, as a sequela to this pandemic, even within the neurotypical individuals,*

with suicidal ideas and [...] panic attacks, anxiety, that we really need to come up with better plans for the mental health illness, with better facilities to address it," (Participant 271).

One participant also mentioned that the road to increasing resources for mental health had already been laid in their community, but that it needed additional support and programming:

"The way New Jersey can help to support the needs of the residents is just continuing to be an ally with different programs to help with mental health."
(Participant 225)

The topic of mental health encompassed many sub-themes, ranging from feelings of hopelessness to finding new forms of self-care and spirituality. Participants often spoke of isolation, secondary suffering, and witnessing the rising death toll of COVID-19 as main drivers of negative mental health outcomes during the pandemic.

Negative Mental Health Outcomes

Content note: The following section includes topics relating to experiences of trauma, depression, grief, and loss.

"While everything around me felt like it was going a million miles an hour, my body felt like it was moving at a snail's pace. It started getting harder and harder to get out of bed. I toyed with a funny little thought in my head a lot. The thought of just vanishing so I wouldn't have to deal with the rest of my day [...] The thought of just ceasing to exist eased the burning in my chest, made the world feel less sad and instead more numb," (Participant 131).

In their experiences, participants shared about the pandemic's detrimental impact on their mental health and emotional well-being, and detailed the various factors that contributed to adverse effects. Participants experienced increased symptoms of depression or anxiety, and for some it was the first time facing these conditions. Many detailed the immense sadness and emotional struggles that the pandemic created or heightened, particularly during periods of quarantine. Stay-at-home orders isolated individuals for days and months at a time, and participants spoke of this isolation in stark terms. *"Emotionally, it's been a wild ride, because we started in this state of shock that this was even happening. Then we moved through a series of false hopes, where we thought things were getting better, and then more things got shut down. [...] And physically, obviously, we've been physically distanced from each other,"* (Participant 025).

Some participants shared a loss of purpose and motivation. Constant fear, the flood of upsetting news regarding COVID-19, and worries about the impact of the pandemic on children took a significant toll. Even some of those who sought out virtual support felt it was not enough. *"Mental health has been a*

big challenge. Talking to psychiatrist on the phone is not the same," (Participant 050). The isolation only created more fear and uncertainty:

"My mental health [is] deteriorating, because I'm stuck in the house all the time. And I can't see some of my family members, can't see some of my friends. "
(Participant 087)

"Just the fear. I think the fear and the loneliness were [...] the things that affected me, very, very much."
(Participant 029)

Secondary Suffering/Trauma

Community members, particularly healthcare workers, found themselves surrounded by suffering and loss even if they did not contract the virus themselves. The pandemic brought not only sickness and death, but also weariness and fatigue as many participants felt there was seemingly no end in sight.

"Not necessarily sadness in terms of [the] emotional, crying type of thing, but more of [...] helplessness. And I mean, even just walking through Newark, seeing trucks of body bags, and you know exactly what those trucks are for. You know why it's happening. Reading the news of all these cases skyrocketing. Just reading about the populations who are super vulnerable to COVID. But that itself, their vulnerability is a result of systemic oppression, like racism, classism, etc. [...] They're just getting perpetuated in COVID, I think that made me feel pretty helpless as well," (Participant 002).

Furthermore, while many participants relied on the news to stay up to date on current events, information, and guidelines, news media offered no hiatus from the rising cases and death toll from COVID-19:

"All the death, it was horrible. Every time you turn on the TV. A neighbor around the street, we lost with COVID. And the death count, every time you turn on the TV and the death tolls just kept raising and raising, and to see all the people who were putting their own lives at risk."
(Participant 003)

Compassion fatigue, or "emotional, physical, and spiritual distress in those providing care to another" (Compassion Fatigue Awareness Project, 2021), was widely reported by healthcare workers who labored for long hours and additional shifts to care for the sick and dying. Participants working in the healthcare field shared their accounts of experiencing stressful and often heart-wrenching situations, confronting a pandemic where much was still unknown regarding best treatment methods. One participant described: *"It would be one after another, and I knew I was used to seeing deceased and critically ill bodies just from being in healthcare since I was 16 years old, but nothing ever prepared me for a time in history like this,"* (Participant 017). Healthcare workers spent days and nights away from their own families, and often were the only face present when patients passed. This painful reality played out thousands of times across hospitals and other healthcare settings.

"These individual human beings were suffering and dying alone, no one is there to hold their hand, and I, along with my coworkers, were the last person they would see or even sense while alive. [...] I became stressed and terrified of going to work knowing I would have to witness people dying alone."
(Participant 017)

"I've been seeing so many people who got sick with COVID-19. It gives you sadness. And it was so scary at the same time because I imagined so many people who died."
(Participant 098)

Despite the many hardships and challenging experiences that weighed on participants' mental health due to the COVID-19 pandemic, participants often demonstrated and shared about finding strength and resilience.

Resilience

"We have seen our students and families be extremely resilient in this difficult time."
(Participant 057)

"Stop looking for everything to be good. [...] Realize that what might appear to be bad – might be the best thing for you. [...] Be thankful."
(Participant 211)

The pandemic sparked a wave of increased vulnerability and helplessness across New Jersey, as it did in places around the world, but it also demonstrated the strength and determination of our collective humanity. This was particularly evidenced by participants who shared how they found support and strength in themselves and their communities, and an overwhelming belief that New Jersey would overcome the pandemic together.

Many participants described instances where individuals in their communities, families, or organizations came together to help and support one another:

"A lot of the families have shown resilience by helping each other out, coming to pick up five boxes of food for people in their neighborhood, and making sure that everyone in their community is supported through our pantry initiative."
(Participant 058)

Individuals also turned inward to keep themselves grounded, and many shared that focusing on what was within their control helped them to address difficult and changing situations.

"My greatest strengths are – I'm very resilient. So, I'm able to bounce back rapidly and adjust to different situations. So that's been a plus, for me. Also, I have the flexibility to change. [...] And also spiritual, and doing my meditation, so that has kept me sane. It has kept me grounded."
(Participant 083)

Participants described personal resilience as well as the resilience they witnessed within their networks and communities, commenting on the support they found from local organizations in responding to the pandemic. This individual and collective strength was a common thread that connected many participants' accounts and contributed to positive outlooks throughout the COVID-19 pandemic.

Positive Outlook

As individuals addressed the challenges of the COVID-19 pandemic, including experiencing social isolation, taking on additional roles at home and in the workplace, and facing loss of employment and sources of income, many discussed areas where they found or maintained a positive outlook.

Participants described taking time for self-evaluations, recognizing and acknowledging personal achievements, or considering the pandemic as a time to work on self-improvement. Many shared their appreciation for the "good" in their lives, as well as the people they were thankful for, contributing to the various silver linings that emerged.

While the pandemic kept many people physically apart, participants recognized the need to connect with others and made efforts to keep in touch with family, friends, and coworkers. Participants shared that finding these support systems was crucial to maintaining a positive outlook:

> **"You kind of have to support one another, for physical, emotional, and mental well-being. [...] As a family, we try to support one another and find some way of connecting through all of this."**
> (Participant 018)

Participants found moments of positivity and gratitude during the pandemic, especially through keeping or finding new employment, and maintaining their physical health as well as that of their family members. One participant explained: *"[I] just try and stay positive. I mean, it almost seems like there's no light at the end of the tunnel. But you know what? You kinda have to keep just living every day as it was before all of this. And I've been trying to work out more since the gym is open. [...] Exercising more has actually helped my head a lot, if that makes sense,"* (Participant 263). Shared another participant, *"No one in my household ended up getting infected with anything. Thank God, you know?"* (Participant 004).

> **"But in a way, I'm lucky because by the grace of God, I'm still able to work."**
> (Participant 035)

Something that may have seemed minor or mundane prior to the pandemic – like eating a meal as a family – was something many participants cherished or found comforting during this time.

"That night I set out all the finest dinner plates and enjoyed my family's company, because now I truly understand that tomorrow is not promised."
(Participant 060)

Many shared that the increased time spent with family members living together in the same space, particularly during quarantine periods, generated moments of happiness. As one participant shared: *"We're gonna get through this. You know, pretty soon we're gonna be able to say this is behind us. And we have each other and [...] I was working, and we were lucky to have some of the normalcy that we had that maybe some people don't have,"* (Participant 021). Another participant wrote within a journal entry: *"The past eleven months are a blur of lazy days, cozy in our home, punctuated by happy moments with [my son]. He is the bright spot in my heart,"* (Participant 259). Individuals shared that, in many cases, staying at home meant gaining precious moments with family members that may not have otherwise been possible.

Self-Care Strategies

While finding ways to cope with the challenges of the pandemic and support their mental health, many participants created new self-care routines.[7] Individuals mentioned several strategies, including frequent video calls with friends, yard work and gardening, finding new hobbies, exercising, spending time with pets, having family dinners and family time, playing board games, taking walks or playing outdoors, and reading or writing.

"I started small projects at home with my daughter. Like painting [...] now that she's back home. I mean, to cope with it we [...] started painting and having fun together, doing things in the routine."
(Participant 349)

Participants who were isolated or living alone found that looking forward to everyday activities and finding a routine helped keep them centered. *"I couldn't see other people. So being able to look forward to the little things throughout the day has actually allowed myself to become stronger in myself, and know that, yes, I can survive on my own. [...] I can find those little things, not in the future, but right now, that are really important to look forward to,"* (Participant 331).

7 Self-care is the necessity to do things that are good for an individual's physical, emotional, or psychological well-being. It means that a person is doing something that helps their body, mind or soul feel good. Self-care is also adaptable – what self-care is for one person will look very different for someone else. This definition was adapted from an interview with Morgan Turner, a licensed independent clinical social worker who sees patients at the University of Washington Neighborhood Ballard Clinic (Cabotaje, 2020).

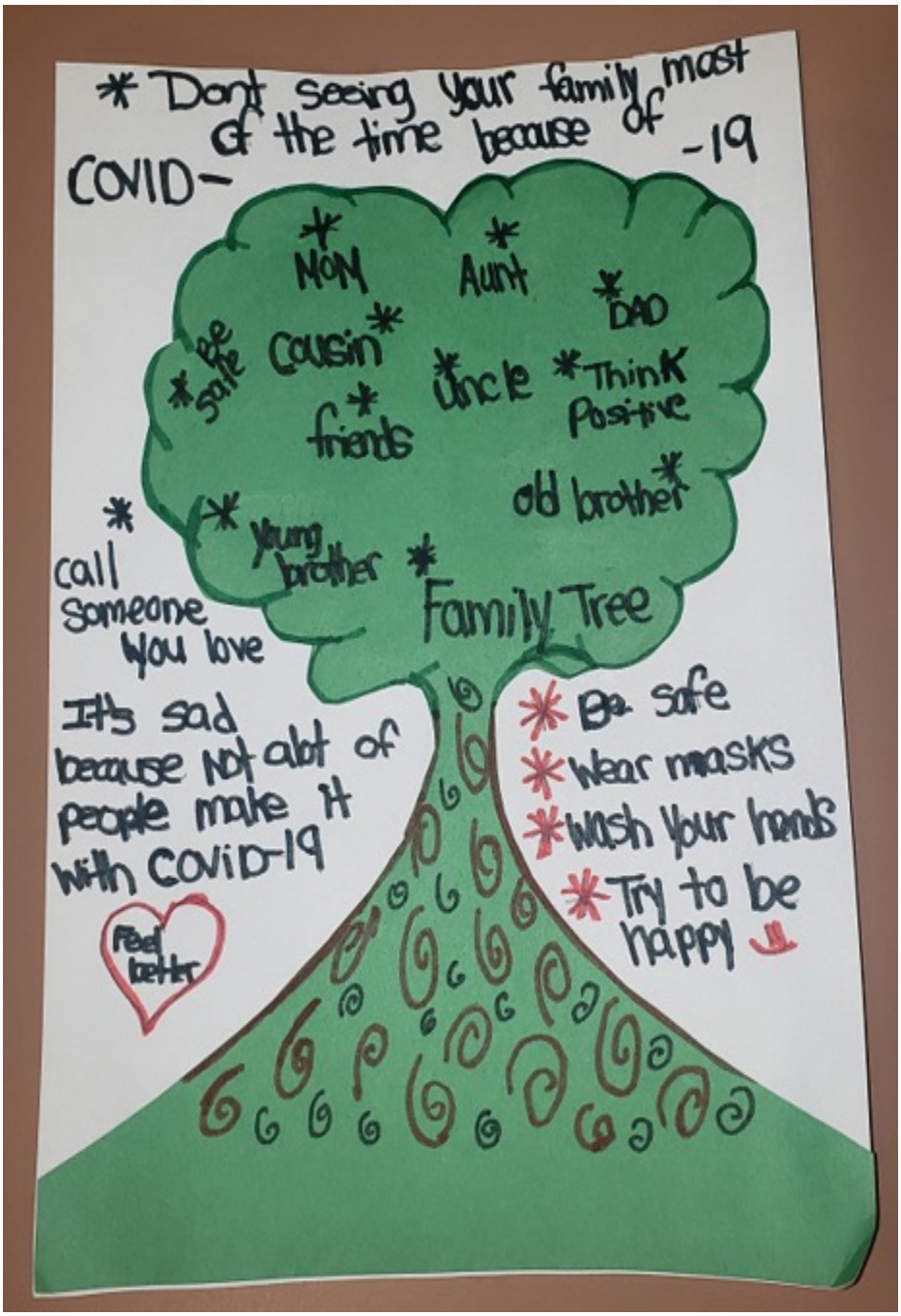
As participants coped with changes in daily life, including reduced access to many places they frequented or activities they participated in prior to the pandemic, finding new strategies and routines to support self-care repeatedly contributed to positive impacts on mental health.

Religion/Spirituality

Among the sources of strength, resilience, and positivity that many participants described, religion and spirituality emerged as a sub-theme as individuals turned to or leaned on their faith to overcome the pressures of the pandemic. Participants prayed for the health of their loved ones and others in their community, as well as for inner strength. One participant shared:

> **"I pray for my wife, my son who works with COVID patients at the hospital, my daughter who helps us daily and all family and friends who are supportive, as well as first responders and health workers, and for the policy makers to work together to help solve this crisis."**
> (Participant 222)

Participants frequently mentioned their faith as a contributor to their personal strength, and their belief in the presence of a higher power for support as they navigated the pandemic: *"I am happy when the day ends and I can thank God by saying,* 'Thank you, God. I finished the day, my day was victorious, and I know that tomorrow it will be the same. If there is a family or a person who is in need of help in some way, somehow, in that way so mysterious that you like to work my God, put me in touch with that person so that perhaps with the little knowledge that I may have, I can shine light on the problem they have,'" (Participant 075.)



Artwork by Participant 461

"Untitled"

Socialization

The United States watched the virus spread through countries around the world before making its way to American communities in January 2020. As the country reeled from the sudden and rapid spread of COVID-19 cases and started to build an emergency response, quarantines and closures resulted in widespread isolation for individuals in New Jersey and across the nation. In their accounts, participants described the various impacts of statewide shutdowns and reduced in-person connections on their daily socialization.

"The pandemic has really changed our lives because you can't do things that you would love to do."
(Participant 014)

"Finding opportunities to connect with people has been hard. [...] I'm alone in the house."
(Participant 048)

"People are isolated and [...] they have no human contact."
(Participant 504)

Social Disconnect

While physical distancing was encouraged by experts and public health professionals as one of the most effective methods to combat the spread of COVID-19, it also led to increased frustration and anxiety for many. Participants shared about communication with coworkers being significantly reduced due to working from home, the pause on in-person learning as remote education began, cancellation of sporting events, and the halt on in-person services at houses of worship. As a result, many individuals were left with very few opportunities for socialization.

Working from home, while simplifying participants' commutes, isolated both colleagues and clients. One participant shared: *"Dealing with COVID, it actually took the personal relationship out of everything I think*

that we do in life, especially at work. Especially when we're dealing with the harm reduction centers, we usually can have a time where we have these conversations with our clients, getting down to the nitty gritty of what they actually need. Now, that's been snatched away from us," (Participant 241).

Individuals also spoke on a more personal note about losing touch with family members and missing these in-person connections. *"I think the hardest thing for all of us, like my family in general, is one, not being able to see them. […] I know we kept talking about offering a solution and saying,* 'Oh, I'm here for you if you need something,' *but not being able to hug them, not being able to kiss them, not being able to be in close proximity,"* (Participant 069).

Another participant, who was unable to visit their family while mourning the loss of a loved one, shared: *"I did have a cousin that passed away a couple of months ago, and it was during all of this and we weren't able to gather. She does live out of state, so I wasn't able to actually go or participate in the funeral. And you know, participating over zoom, no matter how much people try, it's just not the same,"* (Participant 072).

With quarantines in effect, participants described their reduced access to and reliance on former sources of comfort:

"While quarantines and lockdowns were found everywhere, my biggest disappointments were not going to church, the movie theater, my massage therapy, the gym, or health and wellness center. Because those were the core things. […] My whole life was just basically turned upside down. "
(Participant 054)

Many parents and caregivers expressed concern about their children's opportunities to socialize with peers, citing worry about the lasting effects on social and emotional development due to isolation: *"I think that we kept children away from each other for too long. [...] I feel like all of that was just taken away from people very quickly, and people didn't have the opportunity to think about it. We took sports away from kids, we took livelihood away from everybody. We isolated people. I think that's probably the worst thing that we did, as a whole. Everybody isolated […] but we were trying to follow what people told us to do,"* (Participant 021).

Without knowing when the pandemic would end or what the long-term impacts of isolation could be on themselves and their families, many participants – including children – wondered if these effects on socialization would last for years to come.

Child's Perspective on the COVID-19 Pandemic

Artwork by Participant 477

Children

While impacts on socialization due to the COVID-19 pandemic affected individuals across New Jersey, the impact on youth was especially significant. Children had to adapt to learning and engaging in social activities through a screen or while physically distanced outdoors for much of the early months of the pandemic. These abrupt changes in socialization were difficult to understand for many young children. *"It was stressful because the kids could not go outside, to the park or anywhere, because of the pandemic. […] Kids want to go outside and be free so that was the hardest part. They, because of how young they are, don't understand the magnitude of the problem. And even though you try explaining it to them, they aren't able to understand too well. They are who they are, and they want to go outside to play and jump,"* (Participant 097).

Students of all ages missed the essence of being in school, often the primary source of socialization for many youth. *"They miss playing with their friends outside at recess. They miss eating together in the cafeteria. They miss music class when they could sing and not be fearful of spreading a deadly disease. They miss working in cooperative groups. They long for the days when high-fiving wasn't considered a life-threatening gesture,"* (Participant 204).

Children shared their perspectives on the changed landscape for socialization, frequently commenting on the lack of in-person interactions available:

"It was my first year in middle school. We had to go to school online, and that is really hard for me. [...] The worst part of all is that you have to social distance which means you can't see your friends or go somewhere far to see your family."
(Participant 476)

"Being isolated from your friends sucks. It's almost draining being inside and on devices all day, and not having a routine with so much free time left can get boring and mundane."
(Participant 250)

With the reduced amount of activities and opportunities for engagement with others, there were fewer ways for children isolating at home to occupy their time. Many young participants looked to develop new hobbies at home, or find creative ways to stay connected to their peers. Still, for many youth, motivation and focus for school and extracurricular pursuits decreased.

"The kids were also experiencing issues with the lockdown in the house. They totally lost focus of school and not being able to leave the house really hit them. It was hard not to see our family and friends."
(Participant 449)

"I feared that our children would become anti-social. [...] I think it's very important that they have some social experience and [it] helps them with problem solving, making friends."
(Participant 080)

The sudden changes in socialization for children, as well as the unknown long-term effects of the pandemic on youth, were topics of frequent concern for participants. As children and caregivers adapted to the challenges brought about by reduced social interaction and activities, teenagers and young adults in high school and college also navigated their own sets of impacts.

Young Adults

Young adults and adolescents entering transformative periods of their lives during the COVID-19 pandemic, particularly those in secondary school and higher education, frequently discussed feeling as though they were missing out on pivotal experiences: *"It kind of just sucks, all of this. We got gypped of our freshman year, which is [...] supposed to be one of the best years of college,"* (Participant 085).

Participants described these changing circumstances, which differed from the expectations they previously held, as having resonating impacts on their mental health and family relationships. Young adults entering the workforce or receiving technical training recounted the difficulties of learning over a screen, while seeking to strengthen interpersonal connections and mentorship for their future careers.

"I was kept away from my grandma, who's still dealing with my grandpa's death, so it's been very hard for her. And it's hard [...] just not being able to see people on the daily. I haven't been able to get a job either."
(Participant 087)

Older Adults

Many participants shared about experiencing decreased socialization either as older adults themselves, or about older family members that dealt with increased isolation during the pandemic. Often, individuals avoided visiting older relatives and friends, as those over the age of 65 were considered at higher risk for severe illness due to COVID-19. Yet, the reduction of in-person activities for older adults, both within families and at central community hubs, critically impacted the amount of available and accessible opportunities to socialize. *"Who would have thought that [in] my 92nd year of life I would be dealing with such a terrible disease that afflicts so many of my contemporaries? It saddens me that elderly and*

disabled people in nursing homes have been so afflicted by COVID-19, and that they feel very isolated not being able to be with their families at all, except maybe a phone call," (Participant 221).

Regular visiting schedules with family members and loved ones were disrupted for fear of spreading the virus: *"The biggest challenge I've had is actually not being able to see my grandma. She's added in a high risk category, and for the last couple of months, we just haven't been able to see her. If we do, it's with a mask and over six feet apart. I just feel bad because she's older, she's not the healthiest, and just not being able to see her or give her hugs, go to lunch or do anything has been really hard for our family,"* (Participant 412).

Furthermore, while younger people often relied on staying connected through technology, many older adults did not readily have access to digital devices, or had varying comfort levels with using them. Many felt that New Jersey could have done more to support older adults in navigating the pandemic and experiencing heightened isolation.

"In this community alone, [...] I haven't seen anybody come in to make it easier for the seniors, give them hope. [...] It's a senior community, I think they should have some empathy for the seniors."
(Participant 029)

Looking toward the future, participants recommended creating more direct lines of communication and support for older adults and other populations that have experienced increased isolation during the pandemic. *"I think it's really showed us the importance of how people have a need to connect. We've been separated for so long. We're fortunate enough to have quite a bit of family here, but not everybody has several family members in one household. I think there's a lot of seniors, and veterans, and single folks who are truly isolated, and need to have some kind of way to interact, in order to be healthy. Not just physically, but mentally and emotionally. But, of course, you have to balance that with staying safe too. […] The need to have backup plans and backup supplies, and strong leadership that communicates well; that's what we would like to see in the future,"* (Participant 018).

Individuals with Self-Identified High-Risk Health Conditions

Many participants living with underlying health conditions, particularly those categorized by the CDC as at higher risk for developing severe illness due to COVID-19, shared about making difficult decisions to isolate themselves from friends and family. Individuals described the impact that isolation had on their ability to socialize, yet felt it was necessary in order to ensure their own safety and protection.

"I had to start off being quarantined, because I was a kidney patient, and I had gotten pneumonia. [...] My wife's a cancer patient, so we had to be extra careful. We had to do the quarantine for [...] 28 days. We basically tried to avoid going to the grocery store, and going out in places where there is any kind of a crowd or any kind of event."
(Participant 150)

Self-imposed quarantines were made more difficult by the lack of adequate knowledge about and preparedness for the virus, particularly in the early stages of the pandemic. Participants felt unsure about what activities or places they should avoid, and for how long.

"I'm a compromised person, health-wise. [...] I was just trying to figure out all the unknowns of what that could mean, and the looming anxiety of, 'Well, you could get it at any time.' And, being afraid of what you could do or couldn't do. [...] It was lonely. I couldn't see people for a while, until I realized it was safe and took some precautions."
(Participant 191)

One participant shared that many individuals in their community who were immunocompromised or had pre-existing health conditions often did not have a support system available to help access resources while isolating, or daily necessities such as groceries: *"I met a woman who broke down in the parking lot, and shook and cried uncontrollably, because she was sick and she had a heart transplant and she had all these health issues. And she didn't feel it was safe to leave her house, but she needed food, and she didn't know what to do,"* (Participant 194).

The pandemic exacerbated many challenges for those living with pre-existing conditions, as they continue to confront the many uncertainties surrounding COVID-19 and face increased risk of severe illness due to the virus.

Poetry by Participant 257

"A Story of COVID-19"

Days blur into weeks, blur into months

How long since I have seen my grandmother's face?

And how much longer must I wait?

Will my loved ones gather together, or remain distant, longing for the warmth of a hug, the sound of communal laughter, a shared meal…

The world is scared, I am scared.

Lord, protect us all. Heal us. Our country is divided and hurting.

Guide us in living out of our common humanity rather than our isolated individualism.

When one hurts, we all hurt.

What will it take for us to take this to heart?

Let me be a light in chaos and difficulty. Let me persevere in my caution, my patience, my compassion and understanding.

Let us share small signs of love with neighbors and friends.

Let us remember and honor those 400,000 lost amidst this terrible pandemic

Bind us together in love and grant us patience.

Fill us with hope that friendship, the opposite of this lonely isolation, will be ours once again.

Amen

Social Reconnect

"The quarantine that resulted enabled more family time at home. [...] There wasn't a lot of 'running' around being done. There was no obligation to be somewhere and weekends became somewhat relaxed."
(Participant 449)

While the sub-theme of "Social Disconnect" consistently emerged within individual accounts, many participants shared that the pandemic actually increased communications with family, friends, or co-workers, in some cases even strengthening social connections and relationships.

Participants often cited having daily meals together with family as a source of joy in their pandemic routines, as well as a primary means of communicating and coping together with loved ones. As one individual shared: *"The good thing that COVID brought to us was the fact that we were able to sit down every night and have a dinner together. You know, as opposed to before. Everybody worked, so you can't sit down and have a dinner together. […] As a family, sitting down and having dinner, we would have our discussions, […] and we were able to cope,"* (Participant 004).

"Well, unity. Family unity, which is the thing to value the most. Thank God nothing happened to us and we were all healthy. We were home but we were good. That is the most important thing, health, and none of my kids got sick."
(Participant 097)

For participants, technology was a means of connecting or reconnecting with friends and family. Individuals largely relied on video conferencing platforms like Zoom to chat with loved ones, play virtual games as a group, or celebrate birthdays, holidays, and other special occasions. Many participants shared that this provided an opportunity to virtually "see" people they had not been in touch with frequently prior to the pandemic, due to distance or busy lifestyles. Furthermore, for hospital patients undergoing treatment for COVID-19, digital devices were often the sole means of connecting with loved ones on the outside due to safety restrictions on visitations. *"Most hospitals now have policies to ensure safety of patients as well as families, to really prohibit the number of visitors. […] It's a small thing, but not so much so for the patient that is not in their best of health [or] not in a good place, for them to lack the support of their friends and family. […] We have been able to, thankfully, with the help of technology, […] have them still connect via iPads or FaceTime, or things like that, so they can still have some connection,"* (Participant 213).

Several participants spoke about reinvigorating friendships and family connections during the pandemic, as well as gaining a deeper appreciation for the relationships in their lives.

"A lot of group texting with my siblings, we've been doing that more and more. I think in the past several months I have had more contact with my siblings than I had in several years. We're much more aware now that we just can't stop in and see one another or have family gatherings."
(Participant 028)

"I also made it a habit to start talking to my friends more. Even if I couldn't meet them in person, I knew I could FaceTime them, call them on the phone. And because of the free time I had, I was able to make many strong relationships with family that I didn't even use to talk to."
(Participant 169)

For many participants, the time regained with family and loved ones was considered a blessing. *"What made me happy during quarantine was that I got to spend a lot of time with my family, we were always together. […] Seeing everyone get closer together and share a lot of love was just one of the more positive sides of the pandemic,"* (Participant 156). Periods of quarantine inspired reflection on the ways in which people stayed connected in the past, and new opportunities or platforms to connect through moving forward.

Often, participants leveraged the virtual space for building or connecting with their community, convening online for book clubs, exercise classes, and various other group activities or hobbies. *"A completely virtual program […] opened up a window of opportunities for people with IDD [intellectual and developmental disabilities] who had few other options for exercise, nutrition education, and socialization. […] In the past, trainers and clients would go on walks together and had time in between exercises where they could chat and socialize. To make up for this loss, the program team created 'Snack and Chat' events where the participants and trainers would come together via Zoom to make healthy snacks and socialize,"* (Participant 236).

Poetry by Participant 251

"Together"

All of us are stuck at home and bored.

All thinking when will this end?

Can't see your friends, go to school, or even the mall.

Separated by the COVID-19 that surrounds us.

Although we may be apart we are not alone.

Millions of people are being able to connect over video call

Sure it may not be the same but we can make it better

Movie night, staying up all night, spa days, painting classes, escape rooms and more

All from your local bedroom or living room couch.

We're able to spend time with family more than ever before.

Creating and living memories to look back on in the future.

We are making history!

Right in our own homes. Everything we do.

At times we could feel really down and unmotivated but

What really matters is that we will get through this together.

The light at the end of the tunnel might seem dim

But it gets brighter everyday.

There is good in everything

we will make it

Together.

Relationships

Along with the altered social landscape brought about by the pandemic, many participants experienced changes within their interpersonal relationships. While many participants described seeing family members living nearby much less frequently than before, a number of families that lived far apart shared about spending time together on a more regular basis, albeit virtually. Coworkers across state borders could collaborate face-to-face, even when not in-person.

Through the use of technology and community-based platforms, interpersonal relationships were further developed and refined throughout the pandemic as communities navigated the challenges of COVID-19 together. Even standing six feet apart, many people grew closer.

"Families are pulling together, cultivating stronger relationships and sharing resources. I think neighbors, communities are coming together. Three of my neighbors had COVID, and they all recovered. [...] I just feel an even [...] closer relationship with them. I think, through Zoom, and in conference calls or whatever, people are being very creative in connecting."
(Participant 081)

In many cases, families not used to being within the same household for extended periods of time grew closer, and found the pandemic brought them opportunities to learn more about each other. *"Positives? I can say, a stronger family bond. Absolutely. Because without it, I can honestly say we all–my husband included–we all learned different things about each other that we might not have normally had the opportunity to do. We did more family board games, a lot more family time, a lot more conversations. My husband and I, even though the kids are here, we had more time to talk to one another. […] So, we too, [have] grown closer in our relationship,"* (Participant 084).

Acts of Kindness

Despite the challenges and hardships introduced or exacerbated by COVID-19, many participants expressed their empathy for others and exhibited an altruistic spirit. From grocery shopping or cooking meals for neighbors, to regularly checking in on other people's well-being, participants described acts of kindness they performed or received. One participant shared: *"Taking care of an elderly friend, I would make it a point to go to the store for him and leave stuff on his porch. And, just keep touching base with people on the phone. […] People reciprocated that to me as well, and that was huge, just knowing that we were there for each other,"* (Participant 003).

"If you're out there, keep fighting. Try to work with the people in your community, the people that are close to you, that maybe live in the same building as you. Everyone has to work together just to survive right now."
(Participant 050)

Many participants shared resources with those in need, offering food and housing, or donating time, money, or other supports for local organizations and services. There was a sense of community and the need to help one another get through the pandemic. Many individuals spoke to social media posts and flyers from state and local organizations as important means for connecting themselves or others to additional resources. *"Communities have started to stick together, started to have open conversations. Social media has been a platform where people can come together and have courageous conversations and dialogue. […] Our neighbors have stepped up. In terms of an act of kindness that matters to me, knowing that I wasn't able to visit my grandmother, being able to just drop healthy meals off to her so that she would have something to eat and not be fearful of having to get to the grocery store. Acts of kindness around having groceries delivered to our neighbors, to our elders, that means a lot and being able to do that. But, not everyone can afford to do so. So sometimes acts of kindness could be even receiving a card saying,* 'I'm thinking about you,'" (Participant 332).

Artwork by Participant 316

"A Dark Time"

Watercolor and Acrylic

1/8/2021 – 1/24/2021

In this painting I used watercolors and acrylic paint. I used warm colors for that watercolors to show the happiness and lightness I felt before the pandemic hit. Over top of the water colors I painted a thick, black, sloppy line to resemble how fast and strong this pandemic came over us. The black line shows the sudden darkness we all felt over top of us not being able to go out and see friends and family and not being able to continue our way of life that we've known.

Perceptions from Residents and Societal Views/Responses

Throughout the pandemic, individuals developed a wide range of perceptions and responses to the virus, regulations, safety guidance, and behaviors. Participants shared about their opinions spanning from perceived politicization of the pandemic response, fears and frustrations regarding the level of others' adherence to COVID-19 regulations, beliefs about personal and collective responsibility, and concern about the spread of misinformation or lack of knowledge about the long-term impacts of the virus.

"To take care of ourselves, and be very diligent with others. [...] If you get sick, there is a pretty big chain of people who could possibly get sick as well. I think that we have to become more aware of the seriousness of the matter."
(Participant 129)

"I think some people's behavior at times was very disappointing, their choices and how they treated one another. And I understand that's because of the stress of the situation, and people wanting to preserve their personal freedoms and everything, but that was stressful. Because, it makes every time you have to go out to get something a stressful event, even more so than the health risk," (Participant 018).

"It could be less of a problem if everybody worked together as a unit, instead of as a self-contained unit. [...] But, you got people out here that say, 'Oh, we can go party in a group and don't have to wear masks.' No, you puttin' people's lives in jeopardy like that."
(Participant 009)

"There is always fear because this is a lethal virus, it could kill you. But there's always the desire to help, and to know I cannot be selfish. I have medical knowledge and I cannot hide it. If my knowledge serves my community, I will use it and give it to my community. I have my family, I have my children, my husband, and I am asthmatic. I thought, my knowledge is here for the community, but you know we also have to think about our family, right? […] But when I heard my 13-year-old son tell me, 'Don't worry, we'll be fine here at home. Go, because your place is outside helping the community.' *I think that gave me the greatest strength and gave me peace of mind,"* (Participant 074).

Frustrations with a Lack of Adherence to COVID-19 Regulations

Within participants' experiences, many individual views centered around feelings of frustration, and even anger, at New Jerseyans perceived to be disregarding public health measures put in place by state and local governments. Participants often shared markedly negative views or concerns toward others who did not wear masks or adhere to physical distancing guidelines, and many remained fearful about the continued spread of the virus.

"I'm most surprised by the people who aren't taking the correct precautions, and I think it's because they don't fully understand. […] Because for a lot of us – including myself – who got COVID, we were fearful of dying. […] Even now, in Newark, there are police cars with a speaker, saying 'Wear a mask.' *[…] But there are just so many people who still aren't wearing masks,"* (Participant 002).

"[To] half of the population, it's nothing. The other half of the population thinks it's serious. It just boggles my mind that so many people think so differently about a disease that's killed over a hundred thousand, two hundred thousand people in eight months."
(Participant 073)

Participants frequently wished that those around them would take the virus more seriously, with some expressing their perception that others were acting selfishly. Some discussed feeling that they were the only ones in their circles prolonging active efforts to stay protected from COVID-19.

"That's a big problem, that there's so many people–'It's not gonna faze me, I'm gonna do what I wanna do.' And they're the ones that you read about that get the virus and they're no longer with us."
(Participant 003)

"Even now that we're a year out, it's a really eye-opening perspective, when you work in healthcare, and you're there and you see it happening. And then you go out and your friends are in Florida, or they're half across the country and taking flights. You feel frustrated that it seems like you're the only one putting the active effort in to make this stop, and it's just met with people who don't understand or who are thinking about themselves ultimately, and rather very selfish," (Participant 481).

Additionally, many participants reiterated concerns over spiking case counts and increasing mortality rates, and feared risking personal infection from others they perceived to be acting unsafely. This was

especially evident within discussions of returning to work and classes in-person, as businesses and schools reopened. *"I don't feel safe. I'm very concerned about going to a classroom five days a week. […] The way the healthcare system is set up right now, our family insurance is tied to my job. So, we've investigated, can I leave my job and we use my husband's health insurance? But then, suddenly, there's the loss of my income. […] So, I'm feeling disappointed with all that. I'm scared, very scared,"* (Participant 006).

Some participants expressed frustrations toward their own families, sharing instances where family members viewed the virus and its risks differently. One individual emphasized this frustration and disappointment regarding those who did not wear masks, and shared that they put on a mask not only to protect themselves, but their loved ones:

"I don't put on my mask because of me when I leave the house. It has everything and nothing to do with me all at the same time. I wear my mask because I have a niece that I haven't met, I have grandparents that are in their 90s that are still alive, I have two parents that I love, I have in-laws that I love. […] It really puts a lot of things into perspective."
(Participant 223)

Participants also wondered about and shared concerns that actions had not been taken to address and reduce the spread of misinformation online. One individual expressed frustration with inconsistent messaging and denial of the pandemic's existence or severity: *"If there's something I could snap my finger and change, it would be the misinformation. Tired of everybody just lying, and telling people that* 'This pandemic is a hoax. It's nothing.' *Look at what we're dealing with,"* (Participant 073). Another participant shared: *"We can heal our state by thinking globally and acting locally. It is important to be mindful of the fact that we are all interconnected and that our actions not only affect ourselves but also others. We also need to follow the advice of infectious disease experts and medical professionals and only share information from credible sources,"* (Participant 214).

Some participants questioned why measures taken in other countries to address the spread of COVID-19, such as national or area-wide lockdowns or quarantines, had not been instituted early on in the United States. Many participants shared that they wished statewide stay-at-home orders and limitations on gatherings had occurred sooner, and had been all-encompassing or more strictly enforced. Individuals often expressed a belief that earlier action and more stringent or restrictive measures would have had a bigger impact on curtailing the spread of the virus. In retrospect, participants wished for earlier mask mandates, increased contact tracing, and more streamlined leadership and emergency preparedness. *"How is this possible, that we are not prepared for this? By far, I don't understand. And how we all have different opinions. […] If we had just done it from the beginning the right way and just shut in, shut down, it could have helped so much. The way Italy did it. I mean, really, why did we not do that? I don't understand. It's just stupid,"* (Participant 007).

"The leadership of our country, when it comes to just making everyone safe, and not doing, say, a national shutdown. States were just doing their own thing, which kinda set back [...] containing the virus."
(Participant 081)

Many participants shared sentiments that a lack of strong central leadership or consistent messaging led to increased miscommunication and misinformation. *"In the healthcare setting, […] having some discussions with people saying that,* 'This is nonexistent' *– it just shows me that people have not been educated the right way, or not listening to the right resources. So, there should have been, from day one, better clarification [on] where to receive information,"* (Participant 443).

"I'm concerned about the divisiveness in our country in so many ways, but I think the mask thing is emblematic of this divisiveness. Maybe we could have done a better job of [...] communicating, defusing what erupted over masks."
(Participant 055)

As more information emerged about how to control the spread of COVID-19, participants discussed how "pandemic fatigue" increasingly surfaced within their networks and communities, and contributed to their fear of future spikes in cases. *"It definitely takes a toll, where I think healthcare professionals are just exhausted. […] I find myself easily getting frustrated. For example, right now, currently, national experts, local experts, even in my own community, […] we're seeing cases of COVID rise sharper than we would like, even with our vaccination efforts. You get some of the behavior by New Jerseyans – and probably individuals nationwide – they're COVID-fatigued, but the risky behavior puts others at risk. And that is really, really frustrating that at 13 months into this, the risky behavior still continues,"* (Participant 555).

View of Federal Response to the COVID-19 Pandemic from August 2020 to March 2021

"What we didn't know was what some people on the federal level know, i.e. the President, that this was highly, highly transmissible. 'You just breathe,' is the quote. But, we didn't know that. [...] If we knew that February 7th, and the whole state and nation locked down then, I think multiple lives would've been saved."
(Participant 584)

As participants commented on the various levels of emergency response to the COVID-19 pandemic, many shared they felt a lack of support, guidance, and leadership from the federal government. Individuals often expressed that clear direction and a centralized response were largely lacking under the Trump administration's response in 2020, and wished there had been increased preparation and support for communities. Noting the rise in unemployment during the pandemic, one participant shared: *"I think the federal government is very hesitant, and […] I think it's more of a political thing rather than looking at the human being and the everyday aspect, how are they getting through things"* (Participant 070). Participants shared sentiments that this unpreparedness and lack of consistent messaging allowed for the spread of harmful misinformation, and reduced public trust in guidance encouraged by experts and health professionals. One participant stated: *"Dealing with the misinformation and the lack of support from our national public health leaders was also a challenge for me, especially knowing that the leader of our country did not really give us what we were supposed to have,"* (Participant 132).

Many participants echoed this disappointment and frustration with the perceived lack of centralized leadership at the federal level, with some individuals directly referencing former President Donald J. Trump in their accounts:

"I don't have any confidence in the president at all, Trump. I mean, he's just not a leader. He's just – it's Trump. It's like a reality show, and he wants to be the big star of everything."
(Participant 047)

Participants also shared their beliefs on how national leaders could have shaped the response differently, with many emphasizing that unity, as well as advice from scientists and public health experts, should have been placed more explicitly or effectively at the forefront. *"I saw the ebb and flow of attitudes and behaviors based on how information was being presented, and I think the leadership was lacking in terms of empowering people to stay the course and do the best that they could. […] I wished for something from the leadership of our country to encourage us, to be stronger and to endure together, and I think that could have made a difference,"* (Participant 194).

Individuals recalled their concern, as well as surprise, about the perceived lack of planning or preparedness in the federal government's response to the pandemic. Participants often expressed views that the government did not provide appropriate resources, interventions, or protections as the pandemic escalated across the nation. One participant stated: *"I really feel that as a nation, we should have been more prepared for this. Granted, this was unprecedented. No one knew […] such a big life changer could have happened to us, early 2019. But, it's something I feel like as a nation, as a country, if only we had taken more precautions. Perhaps it might not have settled well with everyone, but if only they insisted on some extra precautions, on some plan that could have been executed well, […] I feel like more lives could have been saved,"* (Participant 413). Participants, especially healthcare workers, shared they initially felt

shocked that the government did not have the amount of PPE necessary and readily available for large-scale emergency use.

Participants also spoke about their views related to politicization within the national pandemic response, and often shared sentiments that leaders and decision-makers should put differences aside to lead the nation through the public health crisis in a more unified way. *"The greatest disappointment is that our senate and our government cannot make agreements for the help that we need. […] They need to just put everything aside, whether you're Republicans or Democrats, and just be real people, and not be part of a political party. Just be human, and realize the struggles of what humanity is really going through. We don't have their hundreds of thousands of dollars that they make every day, we don't have cushy cars and jobs. […] We live in a normal society, where we need to rely on each other more than we need to rely on our government, because our government would rather turn their backs on us,"* (Participant 036).

Despite the disappointment and frustration that participants frequently expressed regarding the federal pandemic response, individuals also shared feelings of hopefulness about communities across the country healing, and learning, moving forward.

"I do think that we're on a new horizon, and that does give many hope. But, there's still a long way that we need to go. […] I think that the country has a lot of healing to do."
(Participant 332)

Participants reiterated a belief that looking toward future opportunities for impact, rather than focusing on what could be done differently, would be most productive in steps to move forward as a country. *"I certainly don't want to criticize too hard on anything that could have been done. I'd like to look forward to the future honestly, though. Rather than saying what could have been done, which we all could do, I'd rather say,* 'What can we do going forward?'" (Participant 262).

View of New Jersey Response to the COVID-19 Pandemic from August 2020 to March 2021

In comparison to feedback on the federal COVID-19 emergency response, many participants regarded New Jersey's state response more positively. Individuals often shared they found the efforts of state and local governments in New Jersey to be more cohesively aligned and evidence-based, and more effectively carried out than on the federal level.

"Until the pandemic came, I really didn't know who the governor of New Jersey was. […] Even with some of the comments that people are saying on Facebook about Governor Murphy, he's more informed than the president is to me."
(Participant 033)

Despite a largely favorable view of the state response overall, many participants expressed that New Jersey should have reacted more quickly to the pandemic, and instituted more stringent measures earlier on to curb the spread of the virus. *"I think we could have not waited so long. I think Governor Murphy kind of dropped the ball on it, in a way. […] They really didn't grasp how fast, widespread, that this really took over. It's almost like a zombie movie. […] They really just dropped the ball with not getting out that knowledge as fast as they could've,"* (Participant 036).

Given the many uncharted circumstances and unknowns surrounding COVID-19, particularly in the initial stages of the pandemic, participants frequently asserted that Governor Murphy and his administration did what they could to keep the residents of New Jersey safe and informed. While participants frequently echoed the need for a quicker response and shared wide-ranging feedback for improvement, they expressed an appreciation of the steps taken amid the unprecedented challenges. *"I pray for Governor Murphy all the time, because […] you never could anticipate the pandemic, and all the different layers and the weight, and the dynamics. […] I think I'm proud of our state, I think Murphy did a great job. […] Maybe could have done a better job of the synthesis, of bringing together the human stuff, the health stuff, and the economic stuff,"* (Participant 055).

Participants largely shared an appreciation for the New Jersey government in communicating and prioritizing safety measures such as wearing masks, physically distancing, and taking other preventative actions to help 'flatten the curve' of COVID-19 cases. *"I feel like New Jersey has so far done a very good job, personally, as to curb the numbers. I mean, it's a pandemic, it's gonna spike, and influx and flow. […] Our state government as a whole has done a good job,"* (Participant 027).

Others shared the perspective that New Jersey's state and local governments, as well as local organizations, collaborated effectively to provide emergency resources on the ground, including ensuring healthcare workers had the appropriate and necessary equipment to protect themselves while caring for others. *"I think our highest leaders, from the governor on down, have been very supportive. […] Working in the hospital and seeing when this whole situation initially started, the shortage on PPE was extremely stressful for healthcare workers. So, seeing our local government kind of fight to get those supplies, and the money on the federal level, that made me really happy to see politicians really, truly fighting for the safety and well-being of people,"* (Participant 018). Another commented: *"I guess there's a lot that we don't really know they are doing. There's so many different departments and all. Most of the time, on the news, you only see the bad part. […] Yet, somebody is working behind the scenes, trying to get all that stuff for them. That's their job. […] I've been very proud of Murphy and the way they've been handling things,"* (Participant 047).

Vaccine for COVID-19

Nine months into the pandemic, the United States approved the first COVID-19 vaccine for emergency use authorization (EUA). While this constituted a record-breaking time for vaccine development, the foundation of the COVID-19 vaccine had been built through decades-long research and development, and a global effort to focus resources and information-sharing toward the process. The Pfizer-BioNTech COVID-19 Vaccine was first given the EUA by the U.S. Food and Drug Administration (FDA) on December 11, 2020, followed shortly by the Moderna COVID-19 Vaccine on December 18, 2020. The third vaccine, the single-shot Janssen COVID-19 Vaccine, was provided EUA two months later on February 27, 2021 for individuals 18 years of age and older. The vaccines offered a new line of defense against the virus, but were met with mixed feelings by participants, ranging from anticipation and relief, to fear and even resentment.

Throughout the vaccine development and approval process, before vaccines were publicly available, individuals shared a spectrum of perspectives. Many participants were undecided about receiving the COVID-19 vaccine, and some felt they would wait a bit longer after the vaccines were made available before making a decision. *"I'm kinda on the fence about it. […] I really don't see us getting it. Unless there was more solid facts or more solid proof behind it, and not just assumptions or anything like that– and actual data, that I can particularly see that it's fully working, and also wiping out mass areas of the COVID, then maybe I would,"* (Participant 036).

Following the vaccines' rollout, a divide persisted between those who wanted or had already taken the vaccine by the time of the project's data collection, and those who remained hesitant to receive it. Among participants who were hesitant about the vaccine, individuals largely reported feeling cautious toward any possible lingering or long-term side effects. Yet, individuals who were in favor of receiving the vaccine primarily described them as a way to protect not only themselves, but also others. Many viewed the vaccines as the fastest way to bring an end to the pandemic.

"Hell yeah. If I know it helps the next person, I'm gonna take it."
(Participant 196)

While some participants expressed distrust toward the vaccine due to its quick development, multiple individuals commented on their confidence in science and the process of developing and testing the vaccine. One participant shared: *"The technology and the science that went into creating this vaccine are very innovative, we're very lucky that we've had some very bright, hardworking people that have been working on the technology for these vaccines for years, and have now been able to put that technology to use,"* (Participant 226). For many participants, the potential for more immediate protection offered by COVID-19 vaccination outweighed the perceived risk of possible side effects. *"I think that even though there are many resources that say the vaccine has [the] potential to have long-term side effects, it is*

more important for me to get the vaccine so I can protect my family and my future patients," (Participant 181). Another shared that contracting and recovering from COVID-19 encouraged them to receive the vaccine: *"I was a little hesitant at first, but then I got COVID. So now, they say you have to wait 90 days, because I guess I have immunity still, since it was probably a month and a half ago. But, I think I am, just because I got it so bad. I don't want to do that again. Or God forbid, something worse happens this time. You never know, next time,"* (Participant 552).

Concerns about access to vaccines, or lack thereof, repeatedly came up in participants' accounts. Unequal availability of resources and information persisted throughout vaccine distribution, particularly among minority and low-income populations. One participant shared:

"Belonging to a community of minorities which are of the most mistreated [...] many of us do not have access to a free flu shot and much less so to health insurance. [...] When that [COVID] vaccine comes out, obviously we will not have access to the vaccine as quickly as other groups. "
(Participant 074)

As the vaccines became more widely available, many unvaccinated New Jerseyans attributed their hesitancy to feelings of unreadiness and mistrust in its efficacy. The speed of vaccine development, time and extent of clinical trials, and potential adverse short- and long-term effects were chief among their concerns. *"I will not be getting the vaccine right now. I have a lot of questions and concerns that I can't get answers to. I feel like we are being used as guinea pigs. We don't know any long-term or short-term effects of this vaccine that it could possibly cause. I know in order to get back to a normal life at least 75% of the population needs to be vaccinated, but I won't be part of that population right now,"* (Participant 448).

Other individuals shared they do not need the vaccine as long as they adhere to proper precautions, such as wearing masks and physically distancing, to avoid contracting the virus. As one participant noted:

"I don't need the vaccine. Now, if I was dealing with [COVID], then yeah, I would be trying to get it. But, as [for me] – staying away from other people, and trying to keep myself from getting it, that's why I feel as though I don't need it."
(Participant 038)

Mistrust of the medical community, especially within communities of color, was frequently cited among concerns regarding the vaccine. Many individuals have long experienced and continue to face structural abuse, racism, discrimination, and deceit in systems of healthcare. *"As a Black woman, I know that there's fear in my community around receiving vaccines, and whether or not that's something that people in my family in particular want to do. Because of Henrietta Lacks, because of the Tuskegee Experiment, because Black people have been poorly treated over the years, there's a lack of trust in the community, lack of trust of agencies, lack of trust of public health organizations,"* (Participant 332).

Participants also discussed persistent inequities in healthcare access and health literacy as attributing to varying vaccination levels, some describing differences between neighboring New Jersey communities. *"I live in Bergen County. […] I'm pretty sure, if anything, this is a very health-dominated county in New Jersey. […] Five, ten miles west of us are communities like Paterson, Newark, the Oranges. And it's obvious that those are much less literate, less-income, and I just think that there's a lot of hesitancy and vaccination is met with a lot of resistance. […] These are Hispanic populations, Black populations. And due to healthcare history, there's no surprise as to why these communities are having a difficult time with vaccinating,"* (Participant 481).

As vaccines became available, an influx of information and articles emerged from a breadth of sources. Participants relied on information from health-related entities like the CDC, WHO, FDA, and webpages of vaccine companies, as well as social media, local and national television, and local community centers or community-based organizations. While many participants shared the sources they had come to rely on for trusted information, individuals also commented on the varying availability of information and differences between sources.

"I think it's almost an information overload on some of this. `The Pfizer vaccine has to be kept at a minus something or another degrees.' Okay, I'm not sure how that works, so it raises some issues and questions for me. And then you'll hear, `Well, there are adverse reactions in some people who have gotten the shot.' Well, what does that mean long-range?"
(Participant 217)

Some participants said they mainly received information about the vaccine from their workplaces, particularly evident in accounts from those in the healthcare field. *"I do feel like there is information that the public does not have, unless you're working in public health or working in healthcare. It made me more comfortable about the vaccine, because I got the inside information. […] I think that helped me, because I got some education and knowledge I don't think I would have gotten through a Google search,"* (Participant 514). Participants also shared that more focused efforts were required in distributing vaccine information, especially to those without technology and in under-resourced areas.

While many underserved areas were not granted equitable access to vaccines or vaccination resources, some participants spoke about efforts to prioritize outreach and access for certain communities most affected by COVID-19. One participant shared: *"The disproportionate impact on, for example, young Hispanic men [being] three times more likely to die of COVID than their white counterparts, and African Americans – Black men and women – two times as likely to die from COVID-19 than their white counterparts. The disproportionate impact is overwhelming. So, we are really focusing our vaccine efforts right now in that direction. […] Part of it is not only building awareness, but bringing vaccines to places where they feel safe to receive the vaccine, and then to dispel some of the long-standing and understandable hesitancy. […] To me, those vulnerable populations are the ones that we owe a lot to. And, it should change our response going forward, to making sure that their access to good and appropriate healthcare and prevention strategies are highlighted, emphasized, and delivered,"* (Participant 584).

Participants' perspectives on the vaccine ranged from adamant support to deep fear and skepticism. Regardless of their view on COVID-19 vaccination, participants all shared a concern about the unknown: how the pandemic would continue, or what role the vaccines would play in its outcome.

Those Left Out of the COVID-19 Virus Response

"Our community will always be the most affected. The most battered communities and the poorest communities are the ones who are paying the price in this pandemic, and for all that it entails. Many times, even though we were afraid, we had to go out to work. Why? Because if we don't work one day, then it's a day that we don't eat and that we don't pay rent. That is why many people in the community got sick. I believe that more than 50% of the Hispanic community did not have access to a hospital. Therefore, the statistics are not clear. 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," (Participant 074).

Throughout individual accounts ran undercurrents of racial, social, and economic inequalities, noticed both within the pandemic's varying impacts as well as the emergency response to COVID-19. In responses regarding whether communities had been treated equally during the pandemic, participants frequently mentioned minoritized and marginalized communities they perceived were left out of the pandemic response. Individuals repeatedly pointed to disparities in access to and quality of care, differences in socioeconomic status, and inequities pervasive throughout existing systems and structures.

Many participants indicated that the pandemic had only exacerbated and brought to light pre-existing disparities within New Jersey communities. *"The systems we have in place are inequitable, and so has led to inequitable results. When people of color, specifically Black and Latino populations, are dying at two to three times the rates of their white counterparts, we can clearly see the system is inequitable, we can clearly see the system's not treating these groups the same. And, I think we have to look at the systems we came into this pandemic with. Everything that's happened in this pandemic is a result of things that we came into this pandemic having already constructed,"* (Participant 226).

Some participants acknowledged and expressed concern that these amplified systemic disparities would continue in post-COVID-19 recovery efforts. *"My greatest fear is that the difference between the* 'haves' *and the* 'have-nots' *that we already had, has been so demarcated with this crisis. […] I see so many people in my community, I see the people who come here, who don't have the savings built up, don't have the opportunity to go back to work. […] Even if they can go back to work, how do they get childcare? […] I think that division between people who really need this help is just gonna get worse,"* (Participant 008). Another participant shared:

"There's still gonna be a lot of trials and tribulations after the relief efforts. […] After all that smoke clears, it's still gonna be people here, still with lung damage. And, you know, they're coughing and gagging because they still got to live with it, when all of this is cleared up in certain people's mind space."
(Participant 020)

Participants saw these disparities at every societal level, and frequently mentioned communities of color, low-income communities, and immigrants and undocumented individuals. Participants also mentioned persons experiencing homelessness, older adults, and those who have disabilities, substance use disorders, or who live or work in long-term care facilities, as populations that were further marginalized and disproportionately affected by the pandemic. *"The media just didn't prioritize people with disabilities. […] We talked about how it's having an increased impact on African Americans, and low-income people. We talked about the elderly and nursing homes. But […] very rarely did you hear about people in group homes,"* (Participant 268). Others mentioned the impact on small business owners, as well as essential employees not in the healthcare field, including food service and transportation workers. Many participants felt that these populations were not only the hardest hit by the pandemic, but were also often the last to receive resources or assistance.

"People [...] below poverty level are the ones that may have suffered, because they weren't given the right tools. [...] It's like they were kind of left out. [...] When you disseminate the information and you provide those tools to everybody, everybody should be entitled to those tools."
(Participant 082)

Some participants assumed that the pandemic brought the same level of isolation and uncertainty to everyone, yet many personal accounts detailed a different reality. *"The pandemic […] really has impacted me in terms of being a woman of color, in terms of being a Black woman, and in terms of being a person that has had multiple symptoms, and felt that I was treated unfairly by the healthcare institutions,"* (Participant 332).

Participants also commented on the historic mistrust that many communities experiencing structural discrimination have long held toward societal systems, and that they were unsurprised about the disproportionate impacts. Shared one participant: *"I think in certain areas, people did struggle more than other areas, especially the low-income, the Black, the Hispanic populations, because notoriously they don't get quality services in terms of healthcare compared to their white counterparts. So, I'm not surprised that there's a high incidence of death in the Black and Latino community because of COVID. I don't think the healthcare [was] that great before COVID. […] And then on top of that, to be honest, minorities, especially African Americans and Blacks, we do have a fear of the healthcare system. […] As a community, the minority community, we do have a fear of the doctor. We don't go unless it's really, really serious. And by that time, sometimes there's no turning point, like you waited too long. […] We've been abused with the healthcare system, and we've been neglected, and we haven't been given good treatment,"* (Participant 514).

Many individuals commented on systemic barriers to eligibility for and access to government support or assistance, further exacerbating the impact on communities disproportionately affected by the

pandemic. One participant shared: *"Many people are left out of any resource that the state has provided. […] Immigrants, we are affected by that sort of stuff, from everything like low wages, lack of medical insurance, and adequate housing. They forget to look at the details, we were not considered, and we did not receive fair help even though we all pay taxes, right? So there, you see inequality. And, despite the fact that we contribute to the state, we contribute to the country, we are still not taken into account in these emergency circumstances and yes, we are left out,"* (Participant 076).

Without a social security number or other identification, individuals who were undocumented were particularly excluded from many forms of aid, including income tax assistance. Undocumented individuals also spoke explicitly about avoiding medical treatment due to fear of deportation.

Challenges navigating various barriers to government assistance such as proof of identification were also chronicled by participants experiencing homelessness during the pandemic. *"Homeless youth – it became harder for us to access shelter. NJ 211 required an ID for placement and the DMV was closed. Some shelters were not accepting new intakes and other programs needed some documentations I couldn't provide at the time or couldn't get a hold of,"* (Participant 239). Many commented on the lack of access to COVID-19 testing, struggles to find temporary shelter, and fear of eviction moratoriums ending. As one participant shared:

"The welfare, they should have been more caring or at least have a heart for the homeless people like myself. […] They couldn't even give me any referrals for programs or shelters to go to, I never felt that humiliated or that afraid in my life."
(Participant 462)

Individuals with disabilities or pre-existing conditions also faced significant challenges, as many participants shared that critical supports, routines, or care relied upon before the pandemic were abruptly reduced or put on hold. Parents and caregivers of individuals with disabilities described being in 'survival mode' as schools, day programs, counseling, and other services shuttered in-person activities. *"Your mind is running, trying to cope with,* 'What do I need to do next?' *Trying to communicate with the doctor, seeing what else can we do. Trying to get his medications approved, working with the prior authorizations, medications getting denied. It's just a nightmare. […] Through all these various agencies that we have, at least we could assign one person to one individual, or whatever that ratio needs to be, where you could come in and help in-person as opposed to all this virtual nonsense,"* (Participant 271).

Participants noted that such disruptions in critical services were acutely felt by older adults as well. Despite the population's vulnerability to deleterious impacts of COVID-19, many participants spoke to shortcomings in protecting the state's older adults. Not all had technology access, and many often faced challenges with acquiring basic necessities. Shared one participant: *"Our seniors have been hit tremendously. I feel that they have been forgotten. […] A lot of them don't drive, or have limited mobility, transportation. […] Our most vulnerable population, our seniors 65 and above, are still struggling.*

[Everyday I] speak to individuals who are 80, 90, and they still haven't received the vaccine. They can't log on to the computer, they have no computer, they can't get through the call center, the hotline, and it breaks my heart, it really does. Because I feel like they were kind of forgotten, and it shouldn't have been that way," (Participant 452).

As participants spoke of the populations they felt had been left behind within the state's pandemic response, many took the opportunity to reflect on how decision-makers can improve emergency preparedness and supports for New Jersey communities leading into the future.

Recommendations

"As a nation, we're good at putting Band-Aids on things, but we're never really solving the issues."
(Participant 242)

"I'm concerned that – governments and residents – that we're going to forget. I'm concerned that there's not going to be resources pumped into the public health system, that there's not going to be resources. […] I'm really nervous that in two years, people will look back and say, 'Well, it wasn't really that bad.' *Right? Or,* 'It was kind of a false alarm.' *Or that the takeaway will be the economy should not have closed. […] The reality is we have gutted the public health system nationwide, and in New Jersey. And it's really, really hard to keep any sort of contagious disease in check when you have a skeletal crew that's working around the clock,"* (Participant 555).

In sharing their experiences, many participants commented on the resources needed in their communities and offered recommendations to help guide future decision-making for improvements in public health. These resident-informed recommendations are intended for continued exploration and analysis, and may lay the groundwork for actionable policies and programming moving forward.

Resources Needed

Across their responses, participants discussed not only disparities in access to resources and information, but also a lack of enough available resources in general. Resources such as COVID-19 testing sites, food distribution, housing assistance, and other critical emergency services varied among communities despite the heightened level of need. As one participant shared, *"Not all communities were given the same access, based off of, obviously, zip codes and housing status, health insurance status and income. […] Depending on what you have or don't have, you may have had access to getting COVID screening. If you don't have access to anything, your resources were cut, because we had to limit crowds or, for example, the shelters*

had to cut back on numbers due to social distancing, or whatever restrictions we had in place or still have in place for that matter. […] If you don't have the resources or means to get access, [...] you're not going to get tested because you can't. And then your means of livelihood, whether it's food or housing, those were cut," (Participant 133).

The lack of PPE and resources for healthcare staff, particularly in the early stages of the pandemic, were also prevalent issues. Shared one participant:

"In my lifetime of working, you never could think that you couldn't get a mask or a gown or gloves, and we couldn't. And we were moving ventilators in the middle of the night. [...] We ran out of refrigerated trucks."
(Participant 584)

Participants who worked in the healthcare field discussed wearing the same mask for entire weeks, and vendors even forcing them to bid on PPE. One local mayor asked residents to help sew isolation gowns for workers. An individual shared: *"I sat on a lot of the hospital calls – you had people, [...] trying to get PPE from vendors, but because there was no federal coordination, then they were just trying to out-bid each other. And those that could afford the PPE were able to secure it, which is why the hospitals with lower budgets were not able to procure that PPE. […] This pandemic has highlighted those who have resources, and those who do not,"* (Participant 555).

Others noted the unequal access to COVID-19 testing and restrictive insurance requirements, and recommended that to increase access to testing, health insurance should be disregarded. *"I think we could have tested everyone without restrictions. For example, I know we had some testing sites [where] you needed a prescription from a certain provider within a certain network. That's multiple hoops just to get screened. So, I think if it was just screening for all, regardless of health insurance status, or providers as some individuals don't have a primary care physician to write a script, I think that could have been handled differently,"* (Participant 133).

Participants often expressed there was a need for expanding access to healthcare in general, particularly in reference to improved accessibility and quality within under-resourced communities. *"The state or the country […] have to provide more resources for health. They have to make these resources easier to obtain as a minority group because groups that have purchasing power do not mind making an appointment in a place that is far away,"* (Participant 074). A pattern of recommendations for more equitable, preventative care arose as participants communicated that New Jersey should provide increased support and safety nets for its residents.

"Regardless of having social [security] or not, we all eat and have the same needs, and pay taxes to the state," (Participant 572). Another participant shared: *"I think there was a difference, and that just goes to show how we don't invest in prevention, and in public health enough. […] Health is not just my*

responsibility, but it's also where I live, if there's healthy food available, [...] if I have healthcare or I don't. There's just so many layers that are affecting how we're experiencing the pandemic," (Participant 068).

Participants called for the extension of free mental health and counseling services, and a focus on trauma-informed programming. One participant shared about the potential for such practices in education: *"I think we will be given room to learn more about what trauma-informed teaching can look like, because I am sure there are going to be children who experience varying levels of trauma. I don't think anybody escaped last year, last school year, without some trauma. […] I know I will be meeting some children whose families probably were really disrupted by the pandemic and are experiencing grief and loss,"* (Participant 006). Similarly, calls for harm reduction programs, approaches, and practices arose.

"If all of our programs took more of a harm reduction point of view [and] approach to things, using a harm reduction lens, we would see a lot less disparities in all of our communities and all of our services."
(Participant 245)

Building and incorporating ongoing resources toward addressing loneliness and isolation, particularly for older adults and persons living alone, was also recommended as a critical need. *"I know that the governor has this program where he is trying to get access for every child who goes to school to be able to be connected, as far as digitally, and having the laptop and the connectivity. I want to ask him to include seniors in that conversation. I mean, so many seniors live on fixed incomes, can't afford a $250 bill every month for internet service with TV, or even a smartphone where they can use it and see things. It's just so expensive,"* (Participant 026). There were often calls for internet companies and networks to establish a broadband program to assist individuals and families with accessing reliable internet.

Participants also emphasized the need for improved and streamlined support systems for individuals with disabilities. Participants with disabilities, as well as parents and caregivers, described facing multiple and complicated steps to navigate several different agencies or intermediaries in order to access critical services, noting that challenges with social services were heightened during the pandemic.

"In the sense of the state, there's so many steps, the middle-man, that needs to be completely wiped out. The case managers, you know, some of them care. […] With my daughter, it took me switching three agencies, and within the agency, three different case managers to get to the person who could actually do the work."
(Participant 271)

The onslaught of financial, health-related, and critical resource challenges and limitations was compounded daily for many participants. Shared one person: *"I had to keep constant communication with health insurance and purchase meds off of Craigslist,"* (Participant 239). Another shared about challenges facing intravenous drug users and those with substance use disorders with reduced access to in-person services: *"If individuals weren't able to come and get their supplies, then what choices would they have but to reuse syringes, or use somebody else's syringes, and then we're gonna see HIV be on the rise again,"* (Participant 242). Others commented their concern for children in difficult living situations exacerbated by the pandemic, including a lack of available food at home, or living with their abuser during quarantine.

Resource limitations also meant that those experiencing homelessness, or facing domestic violence or eviction, had reduced access to basic necessities as well as social services or counseling. Furthermore, providers of such critical services called for increased funding, supports, and capacity for continuing to respond to and meet the needs of residents they serve. One participant shared: *"We fall between the cracks as well. So, when you need something, it's like you don't belong to the agency, but you don't belong to the state. […] Ultimately, it affects our ability to serve. It absolutely affects service delivery if you're not giving people the tools and you're not hearing their voices, and not attending to their needs,"* (Participant 279). Another participant commented on the increased demand for additional services needed during the pandemic: *"Since the beginning of the pandemic, our agency has been taking hundreds of live calls for assistance from local residents in real-time […] and the tenor of these calls has increasingly become more panicked and desperate. Families do not have what they need to take care of themselves, and we have seen lines out our door for food and other basic needs,"* (Participant 335).

These tangible limitations led to frustration, and at times, despair. *"I felt like I was one of those people that were at the bottom of the Titanic, and all the rich and the wealthy were up on the top. […] There were also people that, because they were in a position and they were privileged, they were able to have these things that some of us weren't able to acquire,"* (Participant 054).

Many times, the additional emergency resources supplied to communities were not enough to meet the need heightened by the pandemic, and participants shared their views on what sectors and services required increased resources or access.

Increasing Amount of and Access to Resources

Limitations in resources to offset the challenges heightened by the pandemic, including food insecurity, unemployment, learning loss, housing insecurity, and mental health – as well as challenges in accessing such resources or information – emerged throughout participant accounts.

"Some people have access to certain resources that other communities don't. […] It's just a function of our society and how it's set up. It's just unfortunate that some people have fallen through the cracks in terms of the resources they need, across the board. In terms of medical attention, in terms of food, in terms of income sources."
(Participant 121)

Participants expressed that the COVID-19 pandemic called greater attention to inefficiencies in providing resources related to basic needs, like housing. One individual shared their challenges of finding housing through Section 8: *"It's just hard, especially when you don't have guidance. […] When I went down to housing […] they wouldn't let me in, I guess because of the hours.* 'Oh, you have to call over the phone and make an appointment.' *But I called […] in August 2020. They said that they were not accepting no more low-income housing and Section 8,"* (Participant 195). Other participants commented on social service agencies requiring new or additional documentation to obtain food stamps, added paperwork from landlords to apply for rental assistance, insurance or identification to get tested for COVID-19, a social security number to receive economic aid, and immensely long wait times for unemployment assistance – all with no direct contact lines to state agencies.

One participant discussed their difficulty with accessing social services and obtaining support from Medicaid, while navigating outdated systems: *"When the pandemic opened up, it opened up Medicaid and low-income people to get resources available outside their county. […] Over the years, I fell into the low-income stage [...] as well. So, all these things have happened over time, so we were pigeon-holed, if you will, into a system that was built to help the people, but it really was not helping the right way. I mean, it was designed but was not continually managed and grown to keep up with science. So it's antiquated,"* (Participant 483).

Participants frequently echoed a sentiment that although existing systems were not designed to sustain assistance for long periods of time, they were also not built to help people rise out of their situations. Participants expressed gratitude to the individuals and organizations that offered them support with understanding how to obtain resources and navigate complex government systems. Many community-based organizations and service providers increased their outreach to individuals experiencing homelessness, stressing the importance of access to safe and adequate shelter in the midst of an emergency or crisis, and ensuring the provision of food, water, and hygiene kits to those who refuse shelter. Some participants expressed gratitude for the help provided by such organizations: *"They got me in a shelter now […] even though the shelter's crazy, but it's still a blessin' to be off the ground. We stayed in the train station three years, underground, outside in the tunnel. […] They got a lot of resources, and they sent us to a place and they helped us get in a shelter, and food and everything,"* (Participant 200).

Multiple participants shared that they had initiated paperwork for subsidized housing or secured a place to live with the help of social service providers. As shared by one participant: *"The greatest act of kindness that was done for me is that [the social worker] helped me apply for housing […] even though I don't have*

a birth certificate. I was born in the rural south, where birth records were recorded in the family Bible. […] As of November 1, 2020, I have a home to call my own. I am very grateful to everyone," (Participant 099).

Participants reiterated their desire for this type of support to continue after the pandemic. Many suggested the development of a more centralized form for contacting state or local agencies and service providers, and clear communication and guidance on connecting with and accessing resources. One participant shared: *"There could be a more broad, central, clear hub […] where residents know,* 'Okay, if I need help with this, if I need help with anything, I can go to this one central place.' *[…] For those who don't have good Wi-Fi, for those who don't have good access to phones, I would say some central community hub would be a really helpful resource,"* (Participant 475). One participant mentioned investing in current community-based organizations who have deep connections and relationships in their communities to facilitate the dissemination of resources, and reducing the number of procedures or "gatekeepers" to emergency resource distribution. *"That's where it gets tricky for what's going on in a lot of our communities, because there's gatekeepers. […] We were able to reach the resources we needed to distribute the little bit of resources we had. We didn't need you, and how dare you think we had to go through you to give to the people? […] The public sector, the school systems, believe that the civic sector has to ask them or report to them, or give them the opportunity to give to the civic sector,"* (Participant 020).

Increased community outreach and expanded communication, particularly to reduce any duplication of efforts or instances of agencies working in silos, emerged frequently as recommendations. Participants also emphasized the need for community leaders to work together to fight the pandemic, and to combine or coordinate the distribution of resources and support services.

"Everybody's doing their own thing, for their own group, and I don't think that's the way to go. I think if community leaders [...] get together and work together to fight this pandemic, I think we can see more results."
(Participant 152)

While many emergency resources were made available during the pandemic, participants commented on the future of such services, after the temporary funding and infrastructure may be diverted or removed. Participants largely acknowledged that the pandemic has fundamentally shifted or amplified the needs of residents, and that programs and services introduced or expanded during the pandemic should continue.

Social service and nonprofit agencies providing increased aid for residents during the pandemic noted a concern that funds may run out or face budget cuts, and that government relief was often too time-constrained. Within this context, calls for investments in sustainable and supportive infrastructure frequently emerged. *"In August and September [2020], we, as well as all the school-based youth services programs in the state of New Jersey – which are over 90 programs – were in jeopardy of being defunded*

due to the financial burden of COVID-19, and the dire situation the state budget was in. We, in fact, were defunded in August and September, and fortunately reinstated by the state legislature when they agreed on a new budget. So, there was a very good chance that we would not be in existence to support our students' needs, and that was our greatest impact of COVID-19," (Participant 557).

Where more centralized coordination and support did not adequately address community needs, many people and organizations tried to offer what they could locally, and focused on reaching individuals where they were at. One participant shared: *"A typical day, we go out, we start off in some targeted areas that the city has identified where homeless people are at, like gas stations, part of the highway, Route 21, […] different targeted areas that we go in and engage the homeless. We start off with food and water, and then we ask them,* 'How did they become homeless? How long they've been homeless?' *We ask them,* 'What can we do for them?'" (Participant 201). Many participants emphasized the importance of human connection in providing support and resources to address the pandemic's wide-ranging impacts on communities.

Recommendations from Participants

Throughout the COVID-19 pandemic, community members struggled with a receding economy, limited transportation infrastructure, a dearth of adequate and affordable housing, insufficient mental health services, tenuous communication systems, and severe isolation. In response, participants provided recommendations on addressing the many short- and long-term challenges of the pandemic. Individuals largely commented on the need to prioritize and invest available funds toward social infrastructure, including healthcare, education, and housing, and providers such as social service agencies and nonprofit organizations.

One participant commented on the interconnected nature of structural barriers, and the need for social safety nets to support and protect residents. *"I think as a society, we don't have much of a social safety net, right? […] I think, probably, that the federal government has a lot more to do with that than our state of New Jersey, of what New Jersey can do to fix it. Though, we are supportive of overhauling TANF [Temporary Assistance for Needy Families] in New Jersey, so that people are not living impoverished, right? We need to do more to make housing affordable. New Jersey is such an expensive state to live [in]. […] If you experience extreme poverty and domestic violence, you're also at really high risk of becoming homeless. So, I think that we can't really begin to help survivors without creating a more just economic structure in tackling deep poverty and tackling structural racism,"* (Participant 459).

Overall, participants not only spoke to the need for expanded social services, but also for improved and streamlined allocation of community resources in response to emergencies or crises. One participant shared: *"I think that moving forward, just like how we have emergency evacuation, [...] there's certain emergencies that we have protocol for. And I believe, just based on this experience, that there should be a protocol for moving forward [with] something like this, not just COVID-19, but for any type of virus, because I'm sure this isn't the last. It wasn't the first. Something that we could have, [...] just in case this happens again; what's in place for us to do, and how we can do that smoothly without stumbling over each other and trying to figure it out,"* (Participant 122). Participants emphasized that, while the pandemic unearthed or exacerbated deficits and inequities in public and private systems, New Jersey must

undertake and implement major changes in order to better address future crises. Individuals expressed that providers and those on the frontlines of emergencies in particular should have all the tools necessary to respond to another pandemic, and residents should be able to access necessary resources.

One participant reiterated the need for centralized, organized preparation and information, especially regarding safety measures and vaccination: *"I think that you can educate people a little bit better in terms of doing the right thing. For example, I just don't understand why people wouldn't wear a mask. That's number one. Number two, educating people about taking the vaccine. I have several friends who will not take the vaccine. […] So, I think the government could play a big role in educating the people that it's important to take your vaccine, and so important to wear a mask. […] I hope the federal government learned their lessons in terms of anticipating something like that. For example, they cut down a lot of research about vaccines, a lot of funding about things like that, and they could have been better prepared for a pandemic like this,"* (Participant 469). Other participants were surprised at the lack of planning and strengthening of social infrastructure, particularly the education system, in preparation for a crisis. *"I believe that they should have looked closely at our school systems, and how it was gonna affect our children, and what that was going to look like. And even now with the virtual learning, and not having access to certain technology, or if you live in a community where those people may not have access to the internet. Those things should have been well thought out,"* (Participant 122).

For some participants, a return to the "normal" that many had expressed hope for would not be a recovery, but instead a regression toward social systems that were not supportive, just, or equitable. Looking ahead, one participant commented:

"When it comes to social justice and equity, […] 'normal' before was a failure, and we can't go back to normal. And I'm not personally looking to go back to normal."
(Participant 226)

Findings Across Interconnected Themes

Poetry by Participant 466

"Untitled"

the light of march withered;

a disturbance crawled into its heart,

smothering smiles.

and not once did it falter,

in the gloom of spring,

waiting for the end.

Over the course of the seven-month data collection for ***Community Conversations: Pandemic Perspectives***, stories of personal grief, accounts of despair and struggle, and narratives of isolation were shared along with moments of hope and kindness. As key themes emerged connecting participants' individual accounts, three cross-cutting findings arose: **Collective Isolation & Trauma**, **Inequality & Disparities**, and **Unpredictability Now & Into the Future**. Within these findings, a clearer picture can be gleaned of the interconnected nature of participants' experiences and the shared impact of the COVID-19 pandemic on New Jersey communities.

Collective Isolation & Trauma

Throughout the pandemic, individuals and communities were forced to suddenly and rapidly adapt to a changing world. Along with the guidelines to physically distance, participants experienced new or increased feelings and circumstances of isolation and loneliness. Participants discussed the impacts of living alone, working remotely, attending school virtually, staying away from restaurants, movies, and other public spaces, and the reduced capability to travel as factors that contributed to their isolation. This was coupled with economic upheaval and the uncertainty participants felt regarding the duration and direction of the COVID-19 pandemic.

Participants often described persistent stress, grief, and fear due to the changes in their livelihood and increased social isolation, compounding challenges with supporting their emotional and mental well-being.

Individuals discussed their experiences with depression, anxiety, and feelings of sadness during this time. Some participants spoke about the impact of the pandemic on uncovering or amplifying existing trauma, or introducing new trauma. Across the board, participants connected these experiences to the difficulties of adapting to fewer in-person interactions with family, friends, co-workers, support systems, or even friendly strangers. Participants mourned the loss of touch, time, and togetherness.

"I was scared. I'm a recovering addict, I'm in recovery. I also suffer from PTSD, so a lot of stuff was triggered. I'm sharing this because I want other people [...] to know that if they are going through the struggles I've been going through, that it'll be okay."
(Participant 228)

For many participants, the seemingly constant onslaught of death and pain both from the media or immediate surroundings brought on feelings of helplessness. The collective isolation and trauma experienced during the COVID-19 pandemic intensified challenges related to job loss, access to healthcare and basic needs, and relationships with loved ones, and many individuals shared concerns that the impacts would be felt for years to come.

Inequality & Disparities

As focus increased on the pandemic's disproportionate effects on marginalized populations, and critical conversations about racism, discrimination, and other forms of injustice were amplified throughout the country, participants frequently commented on inequalities and disparities present within New Jersey. A strong thread connecting many responses was the discussion of long-present inequities heightened or brought to light during the pandemic. To many participants, these disparities across communities were not only pre-existing, but also deeply integrated and intertwined with present systems.

"Look at the deaths that have occurred, because it is a total inequality. You cannot cover your eyes and say that it does not exist. Our community has lived it firsthand, and cried because of it. [...] Regardless of [...] ethnicity and economic status, there are many things that despite the pandemic, well, there is still a lot of inequality."
(Participant 076)

Frequently, participants conveyed that it was predominantly white and high-income communities that benefited from increased access to materials, supplies, and safeguards, while many historically marginalized or vulnerable groups were left out of the pandemic response. Participants shared that many

already experiencing vulnerability now faced higher risk, as they were less likely to be able to work from home, have access to health insurance, receive paid time off or sick time, rely on savings, or have access to secure and stable sources of income, housing, food, or necessities.

As one participant explained: *"Those with wealth, I think, clearly were able to fare better. So, just for example, if you come down with COVID and you're isolating in your home, the other members of your home can easily quarantine from you. Because you have a large home, you can have a separate bathroom, and they're more likely to protect themselves. But if you have six people living in a 1,200 square foot home, it's just physically impossible. One bathroom, right? There's nowhere to separate. Everybody, most likely, is going to get sick. Additionally, […] if you have a job that provides sick time, you're going to be able to stay home when you don't feel good, and you maybe will be able to quarantine if you're exposed. If you don't show up at work and you don't get paid, you don't have a choice but to go to work when you don't feel good,"* (Participant 555).

Participants' stories and personal experiences spoke to the pervasive and long-present inequities throughout the state and the country, and individuals called on leaders and communities to make a concerted effort to address disparities amplified by the COVID-19 pandemic moving forward, particularly in regards to healthcare and public health. *"That is something that I hope the state of New Jersey, as well as our country, begins to really take a good look at, the connection between healthcare and race, and racism in our country, because it is a systemic problem. […] I hope that this can be an opportunity for us to begin to look at, how do we actually create equity in healthcare systems,"* (Participant 006).

Unpredictability Now & Into the Future

Across experiences, the numerous unknowns related to the COVID-19 pandemic brought about much uncertainty, fear, and concern as participants grappled with new and evolving situations. Participants frequently tied the changes in their personal circumstances to overall societal shifts and unpredictability.

"Throughout all of COVID and whatnot, I had also been in the process of applying to medical school. So, we're adding that layer on top of all this other uncertainty. But I just remember in April, May, March– really all those three months in particular – it just seemed like I was swimming in a riptide. And it's like, no matter how much I'm swimming, there's no light at the end of it. It's like, 'Does tomorrow exist?' *Who knows. And just that feeling of unfamiliarity was kind of scary,"* (Participant 002).

Discussions about unpredictability and uncertainty often regarded not only the virus itself, but also the duration and nature of restrictions on social gatherings, impacts on financial resources, and what sources of information should be trusted or viewed as misleading. Many parents or caregivers navigating their own uncertainties also had to seek ways of explaining the pandemic to their children.

"'Are we going to get killed? What's gonna happen?' Those are the questions I was being asked by my own children."
(Participant 004)

Along with navigating unpredictability, many participants shared they felt distressed and fearful as the pandemic continued, the emotional, medical, and financial burdens on themselves and their loved ones. Participants were often afraid of contracting the virus or passing it to others, and worried about what their lifestyles and relationships would look like as the pandemic wore on. These concerns regarded both immediate circumstances as well as future impacts, including situations of living with an aggressive or abusive partner, navigating depression and mental health disorders, or finding someone to care for their children if they themselves were to become seriously ill or pass away due to COVID-19.

Participants expressed varying degrees of surprise and disbelief related to the unanticipated and sudden impacts of the pandemic. Many individuals restated their negative perception toward the lack of preparation and adherence to protocols or safety measures, and felt the absence of a uniformed response contributed to the pandemic's unpredictability.

"I'm still in shock. I cannot believe that this is the way of the world today. Who would have ever – this is something that I would have never imagined. Had you told me, I would not have believed you."
(Participant 244)

Fear and confusion that arose at the beginning of the pandemic persisted through multiple waves, surges in cases, the emergence of variants, and the devastating loss of lives. Individuals were faced with many questions to which there were often no answers. Participants questioned if and when social interactions and routines would return to their pre-COVID states, if masks and physical distancing would continue, whether future lockdowns would occur, what effects might persist or emerge in years to come, and if the virus would ever disappear.

For many participants, experiencing such unpredictability and the change in expected routines led to feelings of hopelessness and defeat. *"I felt less strong almost the entire time, just because I wasn't really sure of what was gonna happen or what was coming down the road. […] At first I was like, this cannot be reality. So, I felt more defeated […] about things, going to get gas and normal things that I had just got everyday,"* (Participant 021).

Participants also felt the changes were surreal and marked a total disruption in society at large, with many expressing that the pandemic felt apocalyptic. *"There's lines of people getting COVID testing, and they're in hazmat suits, and they're driving up and people are being turned away, and I'm like, is this a collapse of our society as we know it? […] It was–kind of just shifted the way I look at life, I feel like. My big takeaway is, I'll never be the same again,"* (Participant 056a). Another shared, *"We have all been living in a state of almost unbearable, high alert. […] My husband and I wanted to know where our three children were and wanted to bring them close to home with us, because at times it felt like this world was coming to an end,"* (Participant 060).

Some found that the emergence of new strains or COVID variants returned them to initial states of fear, isolation, and uncertainty. One participant expressed that it felt like living in the film *Groundhog Day*, experiencing the early stages of the pandemic over again:

"Now with the new strain of COVID, people are really cautious and really nervous, and no one wants to see each other. It's like 'Groundhog Day', we're sort of reliving it again. We went through the summer and we were able to be social, and now we're going back into isolation again."
(Participant 422)

A large number of individuals also questioned what the new status quo would look like, as the phrase "new normal" emerged frequently. Participants expressed their wonder, and in some cases apprehension, about whether current safety measures would become an integral part of social customs and practice.

Excerpt from Poetry by Participant 357

"Untitled"

What's going to come next?

How's the world going to look?

How can the virus leave all perplexed?

How will we come back after being shook?

Amidst the uncertainty, participants often emphasized that learning from pandemics of the past, as well as reflections on the current COVID-19 pandemic, should guide the preparation and management of emergencies and reduce unpredictability in the future.

"It's gonna take a long time for us to be able to reflect back and say, 'Oh my gosh, this happened.' [...] We're still in it. We don't have the luxury of being able to reflect upon it, because we're not out of it yet."
(Participant 056)

Conclusion

Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project collected the experiences of almost 600 New Jersey participants throughout seven months of the COVID-19 pandemic. The stories and perspectives shared by individuals from all 21 counties reflect the complexities and challenges of life during a global pandemic, as well as the varying perspectives on its range of impacts. Participants discussed the advantages and limitations of the existing public health infrastructure, socialization, the virus response, and the COVID-19 vaccine. Participants offered insights on the resources used or needed throughout the pandemic, provided commentary on state and federal government responses to the virus, and shared recommendations for improving public health and social service delivery. The project also documented firsthand accounts of the experiences of healthcare workers and organizations responding to the virus on the frontlines, and the realities of the persistent and exacerbated inequities experienced by many across the state. As the pandemic continues, these themes not only demonstrate the shared experiences of many New Jerseyans, but can be a guide in the development of comprehensive plans and an equitable path ahead.

These findings can be used to:

- Generate additional white papers and reports that offer a deeper dive into specific themes and sub-themes, supported with additional research and statistics;
- Impact local and state policy, particularly related to employment benefits, family and childcare subsidies, healthcare access, and more;
- Support continued funding of local social programs in under-resourced neighborhoods; to support collaboration between New Jersey YMCA State Alliance, New Jersey Department of Health, and Healthy New Jersey 2030 Advisory Council and Action Teams in developing future policies, programs, and protections to address existing gaps in services across the state;
- Help inform the New Jersey State Health Improvement Plan, as well as Community Health Needs Assessments and Community Health Improvement Plans.

The challenges presented to New Jersey by the pandemic are continual and complex, and thus, solutions must be multifaceted. By ensuring the voices of community members actively guide and inform policies and interventions, ***Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling***

Project is supportive groundwork for community storytelling to be a valuable and indispensable part of New Jersey's progress in public health and health equity.

Selected storytelling submissions and related themes can be accessed at the New Jersey State Library in the "***Community Conversations: New Jersey's COVID-19 Storytelling Project***" digital collection, housed within the New Jersey State Publications Digital Library. The collection may be used only for historical, scholarly, or academic research purposes, and not for commercial purposes. To protect participant privacy, some files are restricted from public dissemination. To access themes from these restricted files, at the discretion of New Jersey YMCA State Alliance, researchers must agree to terms and conditions of a Restricted Data Use Agreement. For more information, please contact New Jersey YMCA State Alliance.

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8 Please note that on June 18, 2021 there was an Erratum published that stated the following: In the report "Provisional Mortality Data – United States, 2020," on page 520, the last sentence in the "What is added by this report?" paragraph of the Summary box should have read, "COVID-19 was the third leading cause of death, and the COVID-19 death rate was highest among non-Hispanic American Indian or Alaska Native persons." The citation for this Erratum is Erratum: Vol. 70, No. 14. MMWR Morb Mortal Wkly Rep 2021;70:900. DOI: http://dx.doi.org/10.15585/mmwr.mm7024a4

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APPENDICES

APPENDIX A: Community Partners Assisting with Story Collection

Arm in Arm

Atlantic City Rescue Mission

Atlantic Prevention Resources, Inc.

Baby Steps Infant/Toddler Child Care Center

Boys & Girls Clubs of Mercer County

Bridges Outreach, Inc.

Bridgeton Public Schools

Camden Area Health Education Center

Capital Area YMCA

Center for Family Services

Central Jersey Family Health Consortium

Commercial Township School District

Community Affairs & Resource Center

Cornerstone Women's Resource Center

Covenant House New Jersey

Deerfield Township School District

Elizabeth F. Moore School

EmPoWER Somerset

Fairfield Township School District

Fairleigh Dickinson University

Fairview Lake YMCA Camps

Garfield YMCA

Generations Family Success Center

Greater Philadelphia YMCA Women's Opportunity Center

Greenway Family Success Center

Hamilton Area YMCA

Healthier Middlesex

Ironbound Community Corporation

Isles, Inc.

Jewish Family & Children's Service of Greater Mercer County

Jewish Family Service of Atlantic County

KinderSmile Foundation

Maurice River Township Elementary School

Metropolitan YMCA of the Oranges

Millhill Child & Family Development Center

Millville High School LINK School Based Youth Services Program

Millville Public Schools

Myron L. Powell School

New Jersey Department of Children and Familes, Division of Child Protection and Permanency

New Jersey Department of Education Cumberland County

New Jersey Department of Health Division of HIV, STD, and TB Services, Harm Reduction Centers

New Jersey Global Advisors on Smokefree Policy

New Jersey Society for Public Health Education

North Jersey Community Research Initiative

Parents Engaging Parents

Partnership for Maternal & Child Health of Northern New Jersey

Phillipsburg Middle School Recreation Education Aspiration Community Health (REACH) Program

Pinelands Regional School District

Piscataway High School

Princeton Family YMCA

Project Self-Sufficiency

Quaran-TEEN-ed PSA Contest

Raritan Bay Area YMCA

Raritan Valley YMCA

Rowan University

Rutgers - Robert Wood Johnson Medical School South Asian Total Health Initiative

RWJBarnabas Health

Salem County Food Pantry Coalition

Social Community Activities Network

Southwest Council

St. John Pentecostal Outreach Church

Student Ambassadors for Community Health - Somerset County 4-H

The Center for Great Expectations

The Center for Prevention & Counseling

The College of New Jersey

The Gateway Family YMCA

The New Jersey Leadership Education in Neurodevelopmental and Related Disabilities Program at the Boggs Center on Developmental Disabilities

The South Jersey AIDS Alliance

Trenton Health Team

United Way of Greater Union County

Victory Assembly of God

Vineland Public Charter School

Vineland Public Schools

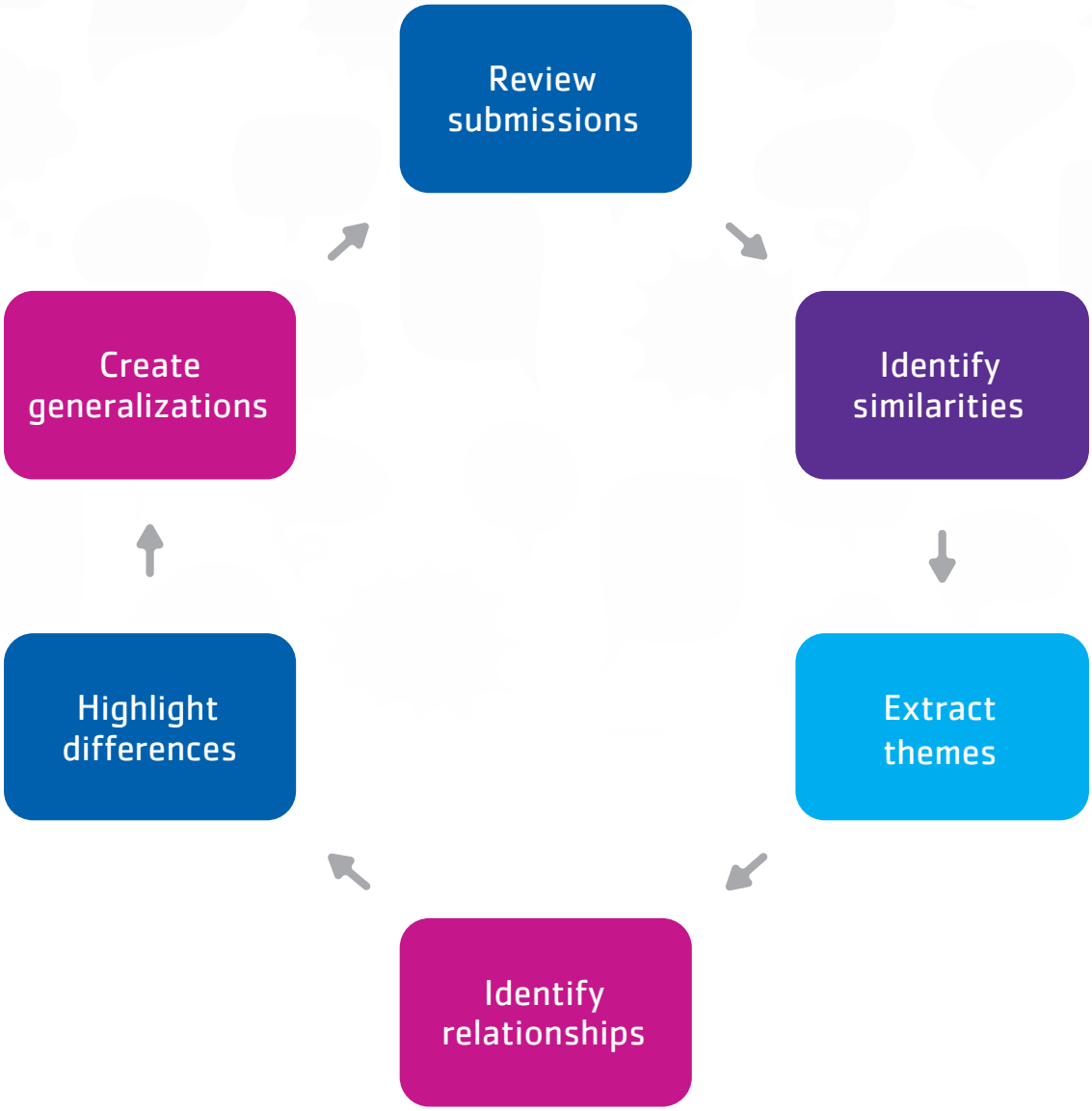
Win! She Speaks

YMCA of Gloucester County

YMCA of Paterson

YMCA of the Pines

APPENDIX B: Qualitative Data Analysis Process[9]



9 Adapted from QSR International: Using NVivo.

APPENDIX C: Qualitative Data Analysis Procedures

WRI utilized the Phenomenology theory, which explains how individuals give meaning to social phenomena in their everyday lives – in this case, the COVID-19 pandemic (Husserl, 1967). The role of phenomenology focuses on exploring how individuals make sense of the world, i.e., the meanings and classifications they use. The fundamental goal of the approach is to arrive at a description of the nature of the particular phenomenon (Creswell, 2013). Typically, interviews are conducted with a group of individuals who have first-hand knowledge of an event, situation, or experience. The interview(s) attempt to answer two broad questions (Moustakas, 1994):

a) What have you experienced in terms of the phenomenon?

b) What contexts or situations have typically influenced your experiences of the phenomenon (Creswell, 2013)?

Other forms of data, such as documents, observations, and art, may also be used. The data are then read and reread, and culled for like phrases and themes that are then grouped to form clusters of meaning (Creswell, 2013). Through this process, researchers worked to construct the universal meaning of the situation or experience, and arrive at a deeper and more nuanced understanding of the phenomenon.

Thematic and analytic coding strategies were used during this analysis (Clarke & Braun, 2013; Ishak & Bakar, 2012). The responses were first grouped into sections aligned with the social determinants of health (SDOH), i.e., health behaviors, clinical care, social and economic factors, and physical environment (please reference Appendix F for the abridged themes and the citations for Robert Wood Johnson Foundation and Healthy People 2030). This was done by completing a summary of each individual submission. This information was used to create the theme nodes. In the next round of analysis, line-by-line coding in NVivo was used, followed by open coding to identify the concepts or themes associated with the SDOHs, and other related themes (please reference Appendix C).

Reliability and validity concerns were addressed, in part, by ensuring that at least two members of the research team conceptualized emerging themes and separately coded each transcript (Morse et al., 2002; Nahid, 2003). Dual coders engaged in each data submission to ensure inter-rater reliability (Glaser & Strauss, 1967; Marshall & Rossman, 1989). In the event of a coding disagreement, the senior researcher/principal investigator was consulted. In addition, intra-coding reliability was enhanced by having each researcher separately code these data at two different points in time.

Phases of Data Analysis

Phase 1: Summary and Overview of Each Submission

The WRI Research Team reviewed all submissions and completed a high-level summary and overview of each individual submission.

Phase 2: Preparation of Codebook

The WRI Research Team drafted a codebook on March 8, 2021, revised it on April 18, 2021 and June 25, 2021 and finalized it on July 14, 2021. As a set of codes, definitions, and examples used as a guide to help analyze data, a codebook is one of the initial and most important steps in the data analysis process (Fereday & Muir-Cochrane, 2006). Codebooks are essential to analyzing qualitative research because they provide a formalized operationalization of the codes (MacQueen et al. 1998; Crabtree & Miller 1999; Fereday & Muir-Cochrane 2006; Fonteyn et al. 2008). Codes are defined as "tags or labels for assigning units of meaning to the descriptive or inferential information compiled during a study," (Miles & Huberman, 1994, p. 56). Like codes, codebooks are developed through an iterative process that may necessitate revising definitions as the researchers gain clearer insights about the interview data. The more specificity in a codebook, the easier it is for coders to distinguish between codes and to determine examples from individual codes. In addition, the more detailed the codebook, the more consistency there will be among coders when using it to code the data/submissions. In this case, the WRI Research Team chose to structure the codebook using four components: code name/label, sub-themes, full definition (an extensive definition that collapses inclusion and exclusion criteria), and an example from the data. An abridged version of the theme guide is included in Appendix F. To view the full codebook, please visit https://www.njymca.org/clientuploads/CommunityConversations/NJYSACommunityConversations-Codebook.pdf.

Phase 3: Coding in NVivo

The qualitative data was examined using NVivo 12 data management and analysis software. NVivo is a software program that facilitates the management and analysis of qualitative data (e.g., helps with the organization of source materials). The software (NVivo) is a tool that assisted the WRI researchers as they drove the qualitative data analysis process.

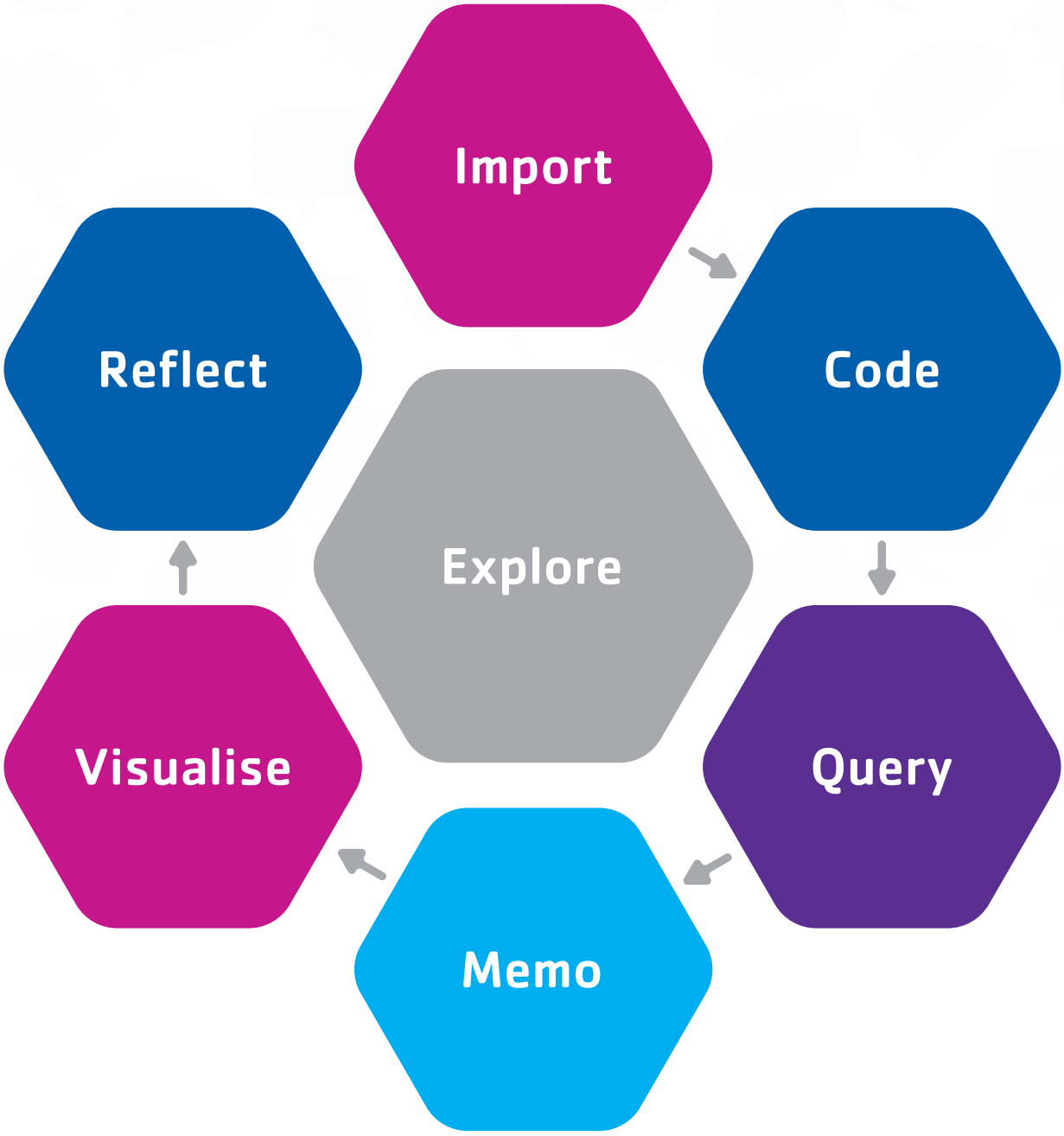
Rationale for using NVivo

NVivo provided a structure and framework, and allowed for the coding of a variety of source materials (e.g., video, audio, documents, and pictures). The program aided in the management of large amounts of data across a substantial number of files (e.g., transcripts, video, audio files); enabled the coding of video and audio interviews directly; and allowed for the sharing of analysis across team members. These features aided in the data organization and analysis processes.

Phase 4: Completed Analysis and Preparation of Final Report

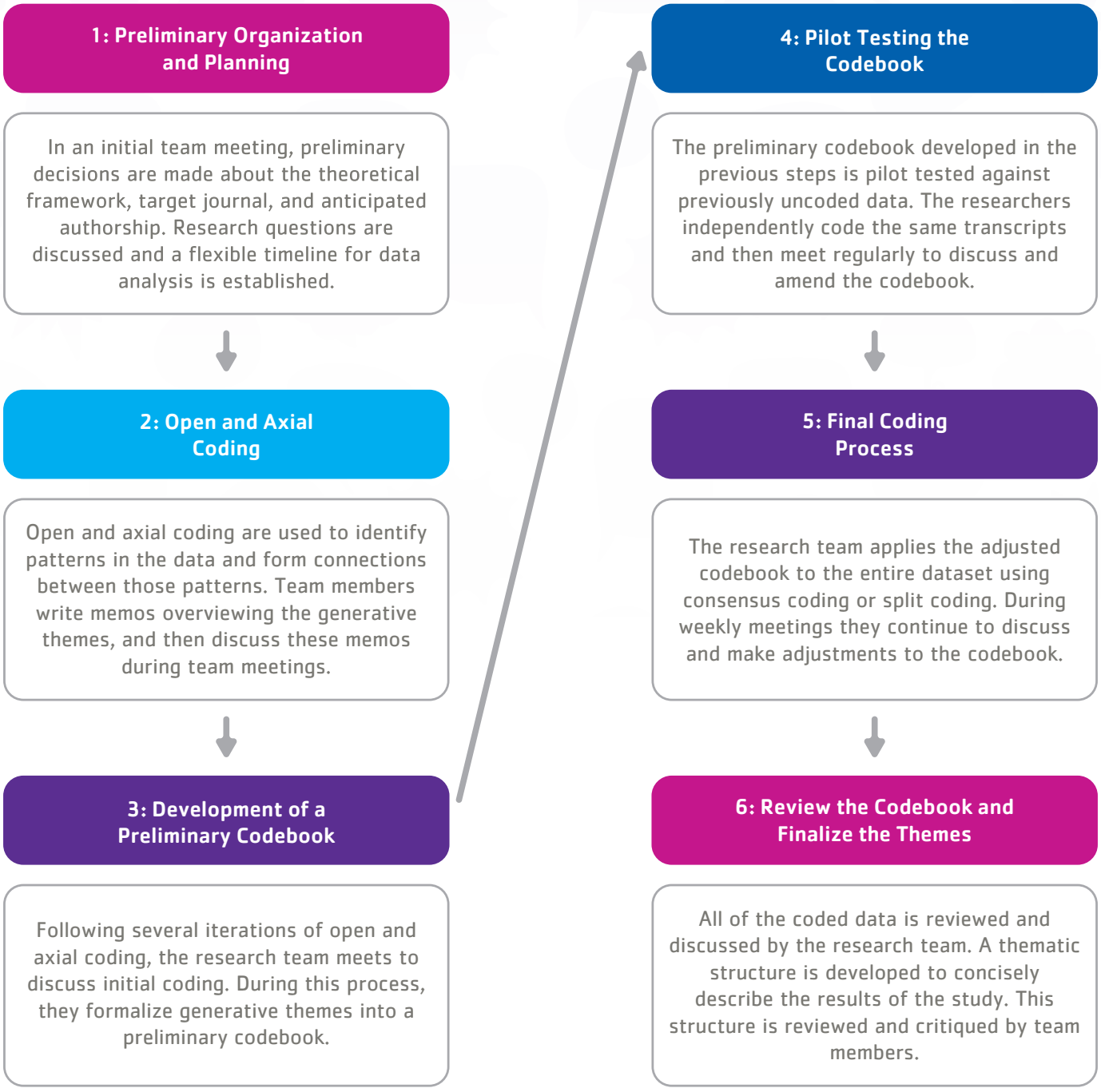
Following line-by-line and open coding in NVivo for all submissions, the WRI Research Team continued to interpret data and revisit the analysis as needed. Analysis of the qualitative data was an iterative and interactive process, resulting in rigorous and systematic interpretation of visual and textual data (Gregory, Williamson, & Barnes, 2020), and this interpretation required an integrated approach (Trochim & Donnelly, 2008). Qualitative researchers must pay careful attention when interpreting data to not lose the voices of vulnerable populations (Ravindran, 2019), and the WRI Research Team engaged in conscious reflexivity to adhere to the voices of the data. Following final analysis, the WRI Research Team engaged in writing sessions to pull data and supporting evidence into the comprehensive final report.

APPENDIX D: NVivo Process Overview[10]



10 Adapted from QSR International: Using NVivo.

APPENDIX E: Visual of Collaborative Qualitative Analysis[11]



11 Adapted from Richards & Hempfill, 2017, Figure: 1 – Overview of the six steps involved in collaborative qualitative analysis. Strategies for enhancing trustworthiness underpin the analysis process.

APPENDIX F: Abridged Theme Guide[12] For Community Conversations: Pandemic Perspectives, NJ's COVID-19 Storytelling Project

Drafted: March 8, 2021; Revised: April 18, 2021; Revised: June 25, 2021; Finalized: July 14, 2021

Social Determinants of Health Categorization per Robert Wood Johnson Foundation's County Health Rankings & Roadmaps[13] and Healthy People 2030[14]

Social & Economic Factors

Topic	Themes	Definition
Social & Economic Factors	**Education**	Challenges with children getting adequate education caused by the transition to remote schooling; Sufficient location at home or lack of space, and reorganizing existing space and resources; Lack of social interaction; Parents/guardians/caregivers taking primary responsibility for children's education because of remote learning and limited access to teachers.
Social & Economic Factors	**Digital Divide**	Lack of access to appropriate or necessary technology (difficulty navigating new technology caused by a shift to remote work/ schooling); Internet connection or access to high-speed internet; Adaptation of teachers, and learning and supporting students; System unable to handle crisis and continued expectation of pre-pandemic productivity.
Social & Economic Factors	**Employment**	Parents/guardians/caregivers at home with young children and needing to assist with remote schooling; Difficulty in procuring childcare for children below school-age, for school-aged children who need help with school and parents unable to work from home, children with differing school schedules, and children with disabilities or IEPs.
Social & Economic Factors	**Financial (In) stability**	Lack of financial means to support basic necessities, including lacking or loss of health insurance; lack of access to food; homelessness or lack of stable shelter; inability to access unemployment benefits, and loss of income.

12 Based on Codebook prepared by Walter Rand Institute. To access full codebook, visit https://www.njymca.org/clientuploads/CommunityConversations/NJYSACommunityConversations-Codebook.pdf.

13 County Health Rankings Model. University of Wisconsin Population Health Institute: School of Medicine and Public Health. Support provided by Robert Wood Johnson Foundation. Accessed from https://www.countyhealthrankings.org/explore-health-rankings/measures-data-sources/county-health-rankings-model

14 Social Determinants of Health – Healthy People 2030. Accessed from https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Clinical Care & Healthcare

Topic	Themes	Definition
Clinical Care	**Access to Care**	Availability and affordability of healthcare services and spaces; Physical ability to access care; Resources available to make decisions around access to care; and loss of or inability to afford health insurance.
Clinical Care	**Quality of Care**	High quality and safe health care.
Clinical Care	**Maternal Health**	Access to prenatal care and care providers, hospitals and safe delivery sites, resources for post-natal care and infant care, and gynecological services and social service providers.
Clinical Care	**COVID-19 Health Behaviors**	Wearing masks, handwashing, social distancing, testing, vaccinations, and self-isolation; Acquiring knowledge and information.

Physical Environment

Topic	Themes	Definition
Physical Environment	**Housing**	Homelessness or lack of stable shelter; Gaining shelter or undergoing housing changes.
Physical Environment	**Transit**	Changes to transportation, including bus schedules, trains, and cars; Access to food and resources, knowledge of where food resources are and ability to get to food sources, and increased curbside pick-up and reliance on personal vehicles.

Additional Themes and Health Factors

Mental Health

Topic	Themes	Definition
Mental Health	**Negative Mental Health Outcomes**	Negative effect of the pandemic on participants' mental health, explicitly or implicitly, including increased anger, frustration, worry, anxiety, depression, stress, fear, and lack of motivation, and behaviors noted by participants.
Mental Health	**Positive Outlook**	Participants share something positive about their experience or a "silver lining," express gratitude for something, or portray optimism.
Mental Health	**Resilience**	Participants cope with difficult situations and portray ability to overcome states of distress and stress.
Mental Health	**Secondary Suffering/Trauma**	Trauma or compassion fatigue experienced by participants; Feelings of sadness or fatigue over someone else's troubles or suffering throughout the pandemic.
Mental Health	**Self-Care Strategies**	Supporting physical, emotional, or psychological well-being through self-determined activities, including new hobbies, playing games, exercising, and cooking.
Mental Health	**Religion/ Spirituality**	Hope or strength attributed to some aspect of religion, faith, or spirituality.

Socialization

Topic	Themes	Definition
Socialization	**Social Re-Connect**	Increased communications with family, friends, and acquaintances; Strengthening social connections and relationships with children, parents, and friends as a result of COVID-related impacts, including quarantine, remote learning or working from home, and extra time together.
Socialization	**Social Disconnect**	Social disconnection by objective measure of having little or no social contact with others, leading to feelings of loneliness and perceived experience of social isolation; Discrepancy between actual and desired social connection; Distance from family and friends; Impacts detailed for children, young adults, older adults, and individuals with self-identified high-risk health conditions.
Socialization	**Relationships**	Response to specific questions by the data collectors, to describe one act of kindness that was done for participants, and one act of kindness that participants did for someone else.

Perceptions from Residents and Societal Views/Responses

Topic	Themes	Definition
Perceptions from Residents and Societal Views/ Responses	**Frustration with lack of adherence**	Frustration and anger at those who will not wear a mask or social distance, or follow mitigation measures and public safety regulations.
Perceptions from Residents and Societal Views/ Responses	**Perceived politicization of recommended public health response**	Lack of adherence to public safety regulations attributed to perceived political affiliation, or pertaining to a political divide within perceived public responses.
Perceptions from Residents and Societal Views/ Responses	**View of New Jersey Response to the COVID-19 Pandemic**	Participant perceptions regarding the NJ government's response, including statewide shutdown order, resource allocation, and road to recovery.
Perceptions from Residents and Societal Views/ Responses	**View of the Federal Response to the COVID-19 Pandemic**	Participant perceptions regarding the federal response, including federal communication and guidance toward COVID-related safety measures, and provision of supplies for health care workers.

Those Left Out of the COVID-19 Virus Response

Topic	Themes	Definition
Those Left Out of the COVID-19 Virus Response	**Those Left Out of the COVID-19 Virus Response**	Response to specific questions by the data collectors, regarding whether all communities have been treated equally during COVID, if there were populations favored over others, and who participants thought were left out of NJ's emergency COVID response and why; populations within responses included communities of color; disabled individuals; homeless individuals; low-income communities and individuals; older persons; undocumented individuals; veterans; and individuals facing language barriers.

Additional Topics

Topic	Definition
Vaccine for COVID-19	Broad category in which participants discuss their view on the COVID-19 vaccine, and felt the statewide divide over the efficacy of vaccines.
Recommendations	Broad category in which participants offered their own recommendations for moving past the COVID-19 pandemic.
Resources Needed	Catch-all of participant views regarding what resources are needed and where in their communities.

APPENDIX G: Themes and References in the Data

Theme	Number of References
Clinical Care & Healthcare	183
Access to Care	238
Loss of Health insurance	38
Maternal Health	80
Infant and Child Health	42
Quality of Care	46
Health Behaviors	81
COVID-19 Health Behaviors	2,669
Mental Health	130
Negative Mental Health Outcomes	919
Positive Outlook	1,219
Resilience	575
Religion or Spirituality	260
Secondary Suffering and Trauma	460
Self-Care Strategies	326
Social Disconnect – Social Isolation & Loneliness	1,020
Children	105
Individuals with High-Risk Health Conditions	70
Older Persons	80
Young Adults	30
Social Re-Connect	588
Relationships	98
Acts of Kindness	780
Social Pods	63
Perceptions from Residents and Societal Views/Responses	112
Frustrations with Lack of Adherence	262
Perceived Politicization of Public Health Response	74
View of NJ Government's Response to the Pandemic	463
View of the Federal Government's Response (in 2020)	244
Physical Environment	20
Housing	62
Housing Insecurity and Instability	191
Transit	36
Mode of Transportation	22
Food Accessibility	20

Theme	Number of References
Food Insecurity	107
Social and Economic Factors	1,480
Digital Divide	152
Factors Impacting the Digital Divide	78
Education	365
Challenges with Remote Schooling and Virtual Learning for Children	396
Parents or Guardians or Caregivers Functioning as Teachers	101
Employment	426
Childcare Arrangements	81
Financial & Economic (In)stability	131
Lack of Financial Means to Support Basic Needs	94
Loss of Job or Business	211
Those Left Out of Virus Response	288
Communities of Color and Minoritized Individuals	101
Disabled Individuals	168
Homeless Individuals	114
Language as a Barrier	42
Low-income Communities	68
Low-income Individuals	68
Older Persons	47
Undocumented Individuals	62
Veterans	3
Vaccine for COVID-19	499
Recommendations	259
Resources Needed	471
Actionable Items from Residents	26
Unpredictability	898
Noteworthy Quotes for Report or Presentation	82

APPENDIX H: Community Conversations Guiding Questions

1) How has your life changed since March (2020) as a result of the COVID-19 pandemic?

2) What were the main or most trusted sources you received information about COVID-19 from? How did you act upon the information you received? Have you developed any new sources of information?

3) What was the hardest/biggest challenge for you or your family during/amidst COVID-19?

4) With many aspects of daily life going virtual, what types of technology, or digital resources, have you relied on?

5) Please describe any challenges you faced in accessing technology or digital resources during the pandemic.

6) Have you experienced any difficulty navigating resources or information related to a language barrier? If so, please explain.

7) In what ways did you address the challenges of COVID-19? What challenges do you expect will remain post-COVID-19?

8) Who were your allies? Who were you able to lean on?

9) What were your greatest sources of strength? Where/when did you feel less strong?

10) What brought you/Where did you find happiness?

11) What brought you/Where did you find sadness?

12) What were your greatest disappointments as a result of the pandemic?

13) What surprised you about the pandemic?

14) What are your greatest fears moving forward?

15) Please describe one act of kindness that was done for you.

16) Please describe one act of kindness that you did for someone else.

17) Did you have any conversations with healthcare or other service providers about COVID-19? What did this conversation look like? Who said what?

18) What COVID-19 resources are you aware of, or have you benefited from?

19) Do you know where you can get tested for COVID-19?

20) What have you learned, or where have you received information about COVID-19 vaccine development?

21) When a vaccine for COVID-19 is made available to the public, would you choose to receive it? Why or why not?

22) Do you think that all communities have been treated equally during COVID? Were there populations who were favored over others?

23) Who do you think was left out of NJ's emergency COVID response? Why were they left out?

24) What do you think NJ could have done better?

25) If there was one thing that you or someone else could have done differently, what would it be?

26) Is there anything else you would like to share that was not asked?

APPENDIX I: Community Conversations Guiding Questions (Guía De Preguntas Para Conversaciones Comunitarias)

1) ¿Cómo ha cambiado su vida desde marzo (2020) como resultado de la pandemia COVID-19?

2) ¿Cuáles fueron las fuentes principales o más confiables de las que recibió información sobre COVID-19? ¿Cómo actuó con la información que recibió? ¿Ha desarrollado nuevas fuentes de información?

3) Dado que muchos aspectos de la vida diaria se vuelven virtuales, ¿en qué tipos de tecnología o recursos digitales ha confiado?

4) Por favor describa los desafíos que enfrentó para acceder a la tecnología o los recursos digitales durante la pandemia.

5) ¿Ha tenido alguna dificultad para navegar por los recursos o la información relacionada con la barrera del idioma? Si es así, explique.

6) ¿Cuál fue el desafío más difícil / más grande para usted o su familia durante / en medio de COVID-19?

7) ¿De qué manera abordó los desafíos de COVID-19? ¿Qué desafíos espera que permanezcan después de COVID-19?

8) ¿Quiénes fueron sus aliados? ¿En quién pudiste apoyarte?

9) ¿Cuáles fueron sus mayores fuentes de fortaleza? ¿Dónde / cuándo te sentiste menos fuerte?

10) ¿Qué te trajo / dónde encontraste la felicidad?

11) ¿Qué te trajo / dónde encontraste la tristeza?

12) ¿Cuáles fueron sus mayores desilusiones como resultado de la pandemia?

13) ¿Qué le sorprendió de la pandemia?

14) ¿Cuáles son sus mayores miedos de seguir adelante?

15) Por favor, describa un acto de bondad que alguien hizo por usted.

16) Por favor, describa un acto de bondad que hizo por otra persona.

17) ¿Tuvo alguna conversación con el cuidado de la salud u otros proveedores de servicios sobre COVID-19? ¿Cómo fue esta conversación? ¿Quien dijo que?

18) ¿Qué recursos de COVID-19 conoce o de los que se ha beneficiado?

19) ¿Sabe dónde puede hacerse la prueba de COVID-19?

20) ¿Qué ha aprendido o dónde ha recibido información sobre el desarrollo de la vacuna COVID-19?

21) Cuando una vacuna para COVID-19 esté disponible para el público, ¿elegiría recibirla? ¿Por qué o por qué no?

22) ¿Crees que todas las comunidades han sido tratadas por igual durante COVID? ¿Hubo poblaciones favorecidas sobre otras?

23) ¿Quién crees que quedó fuera de la respuesta de emergencia de COVID en Nueva Jersey? ¿Por qué quedaron fuera?

24) ¿Qué crees que NJ podría haber hecho mejor?

25) Si hubiera una cosa que usted u otra persona pudieran haber hecho de manera diferente, ¿cuál sería?

26) ¿Hay algo más que le gustaría compartir que no haya sido solicitado?

About New Jersey YMCA State Alliance

New Jersey YMCA State Alliance is a coalition of 31 independent YMCA associations. Through public policy, statewide initiatives, strategic partnerships, and service delivery, the Alliance fosters a greater ability for YMCAs, community partners and thought leadership across the state to impact families, improve community health and advance equity. Our collective voice strengthens local communities while promoting youth development, healthy living and social responsibility. For more information, visit njymca.org.

About The Senator Walter Rand Institute for Public Affairs (WRI)

The Senator Walter Rand Institute for Public Affairs (WRI) at Rutgers University - Camden is a research and public service center that provides evaluation, technical assistance, and data services to our community and academic partners. With two decades of experience in southern New Jersey, the WRI collaborates with public, private, and nonprofit sectors to provide accurate, accessible, and actionable information to support evidence-based decisions about programs and policies.

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