



Harvard Law School  
Project on Disability



SOCIAL CONNECTEDNESS  
FELLOWSHIP PROGRAM

# **The Experiences of Persons with Intellectual Disabilities Living in Massachusetts Group Homes During the COVID-19 Pandemic**

**A Participatory Action Research Project**

By Diana Mairose and Tony Phillips  
*with support from Anne Fracht and Hezzy Smith*

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## EXECUTIVE SUMMARY

This research was created by two self-advocates with intellectual disabilities who wanted to understand the experiences of people with intellectual disabilities living in group homes during the COVID-19 pandemic. There is little research or literature on people with intellectual disabilities living in group homes, and even less research conducted by researchers with ID. We chose to interview and connect with this group because we believe their stories and experiences deserve to be heard. We also believed that persons in group homes may have experienced greater social isolation or greater barriers to accessing the community during the COVID-19 pandemic than persons with intellectual disabilities either on their own or with family members. We also know that people living in group homes experience unique barriers to societal inclusion, and are often harder to reach. Ensuring the voices of people with ID are heard, understood and taken into account when we discuss social connectedness is crucial to us. At the core, our research seeks to ensure that the voices of people with ID in group homes are heard.

We reviewed some of the research literature on the experiences of persons with intellectual disabilities (ID) during the COVID-19 pandemic and then interviewed six persons with ID who have been living in group homes in Massachusetts during the COVID-19 pandemic. We found that they had experiences similar to those reported by other researchers on the COVID-19 pandemic experiences of persons with ID, including feelings of isolation or loneliness due to disruptions in their daily routines and activities. Three interviewees lost their mothers to COVID-19, which exacerbated their feelings of loneliness. We also found that people with ID had a variety of experiences. For example, some people we interviewed reported coming into avoidable contact with staff or day program participants who had COVID-19 symptoms. Some of them appeared to have caught COVID-19 because of these contacts. At the same time, for most people we interviewed, their group homes' rules during the pandemic meant they had much less choice and control over basic aspects of their lives, including their ability to go outside their homes.

It wasn't all bad though. Some of the people we interviewed moved into new residences they liked better. Some people also decided to stop attending day programs and do more paid work from home. One person shared that he had become more spiritual during the COVID-19 pandemic, by joining a Bible study group and attending services online. Others developed new romantic relationships during the pandemic, and one person became pregnant.

We wish that we had been able to include people with legal guardians in our research project. We did not do so because the rules about human subject research ethics impose more requirements for human subjects who need someone else to consent to their participation in research activities. We think

that they also have important experiences and perspectives that should be explored and shared.

We believe it is important that researchers follow the spirit of “nothing about us without us” when they do research about persons with ID. The conversations we had were especially rich because persons with ID were asking the questions. Our views matter, and researchers without ID should find ways to include people like us in their research.

## ABOUT THE AUTHORS

We are both self-advocates who have intellectual disabilities (ID) and have advocated both for ourselves, and also for the rights of persons with ID, for decades. Our experiences as self-advocates, as well as our personal experiences during the COVID-19 pandemic, have helped to influence our research during this fellowship, both in terms of our research topic and our methods.

Diana is a board member of [Self Advocates Becoming Empowered](#) based in Ohio. She also works at Hamilton County Developmental Disability Services, where she has supported persons with disabilities who live both in and outside of group homes to access housing options. Both before and during the pandemic, she has worked to empower persons with disabilities to tell their stories.

Tony is the president of the [Self-Advocacy Association of New York State](#) and is based in New York City. He now lives in his own apartment, but has lived in a group home in the past. He credits his experiences advocating for himself and others at that group home for introducing him to the self-advocacy movement. He also spent the first 18 months of the pandemic in a nursing facility against his will, where he experienced many of the same kinds of restrictions that persons with ID living in group homes faced.

## INTRODUCTION

We know that persons with intellectual disabilities (ID) are often left out of many areas of life, including research. We also know that persons with ID often experience situations, like the COVID-19 pandemic, differently than people without disabilities. Too often, persons with ID do not have opportunities to share their stories, especially harder-to-reach persons with ID who live in group homes. Our primary research question was: What were the experiences of persons with intellectual disabilities who were living in group homes in Massachusetts during the COVID-19 pandemic?

### **What Other Research on Persons with ID during the COVID-19 Pandemic Says:**

We worked with [Hezzy Smith](#) and [Anne Fracht](#) from our partner organization [Harvard Law School Project on Disability](#) (HPOD) to review the research literature related to our research topic, to learn about the ethical rules for human subjects research, and to organize and conduct our interviews and focus group discussion.

We also received support from [Massachusetts Advocates Standing Strong](#) (MASS). We discussed the research literature related to our topic with three MASS self-advocate research fellows, who are part of HPOD's [Self-Advocates in Research Initiative](#). We shared with them our reflections on the interviews that we conducted.

We reviewed nine research studies that have explored the experiences of persons with ID during the COVID-19 pandemic. We found that few researchers appeared to identify as persons with ID, few researchers talked directly with persons with ID as part of their research, and researchers who did talk to persons with ID did not talk to many persons with ID who were living in group homes.

We wrote down some of our other [reflections on this research](#) and published them on the HPOD website earlier this summer. We found the following, first that researchers were less likely to speak with persons with ID directly and instead focused on the experiences of people around people with ID<sup>1</sup>. “Researchers did not always seem to choose methods that make it easier for persons with ID to participate in the studies, such as open-ended interviews”<sup>2</sup> in contrast, we chose to use open-ended interviews to allow interviewees the space to guide the conversation. Researchers often overlooked the strength, resiliency and creativity of people with ID to handle complex challenges such as the COVID-19 pandemic and instead focused just on the negative effects of the COVID-19 pandemic **on** people with ID.<sup>3</sup>

Importantly, we found that persons with ID did not seem to be included in conducting the research about persons with ID. Some of the research we

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<sup>1</sup> Mairose & Philips, “Self-Advocates’ Reflections on Research about COVID-19 and Persons with Intellectual Disabilities”, Harvard Project on Disability, July 2022, p. 1-3.

<sup>2</sup> Mairose & Philips, “Self-Advocates’ Reflections on Research about COVID-19 and Persons with Intellectual Disabilities”, Harvard Project on Disability, July 2022, p. 1-3.

<sup>3</sup> Mairose & Philips, “Self-Advocates’ Reflections on Research about COVID-19 and Persons with Intellectual Disabilities”, Harvard Project on Disability, July 2022, p. 1-3.

reviewed focused on the experiences of other people in the lives of persons with ID.<sup>4</sup> But researchers who focused on the experiences of persons with ID did not speak to persons with ID directly.<sup>5</sup> One group of researchers tried to get input from persons with ID, but they combined it with inputs from others, too.<sup>6</sup> Even where researchers spoke to persons with ID directly, none of the researchers seemed to identify as persons with ID.<sup>7</sup> After reviewing this literature, we believed that there were definite gaps that we could fill. The two main gaps we sought to address are the inclusion of people with ID in the research process, and interviewing people with ID rather than those around them to understand **their** experiences.

### ***How We Approached Our Research***

Next, we set out to interview persons with ID who have lived in group homes in Massachusetts during the COVID-19 pandemic, to understand what their experiences have been like. We chose group homes because we believed individuals living in group homes would have less autonomy over their choices, be more socially isolated and possibly further removed from the broader

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<sup>4</sup> e.g., Vereijken et al., 2022; Embregts et al., 2021; Scheffers, 2021; Patel et al., 2021

<sup>5</sup> e.g. Scott D. Landes et al., "Covid-19 Outcomes among People with Intellectual and Developmental Disability Living in Residential Group Homes in New York State," *Disability and Health Journal* 13, no. 4 (October 2020): p. 100969, <https://doi.org/10.1016/j.dhjo.2020.100969>., Sam Tromans et al., "Priority Concerns for People with Intellectual and Developmental Disabilities during the COVID-19 Pandemic," *BJPsych Open* 6, no. 6 (October 29, 2020), <https://doi.org/10.1192/bjo.2020.122>.

<sup>6</sup> Patricia Navas et al., "Supports for People with Intellectual and Developmental Disabilities during the COVID-19 Pandemic from Their Own Perspective," *Research in Developmental Disabilities* 108 (January 2021): p. 103813, <https://doi.org/10.1016/j.ridd.2020.103813>.

<sup>7</sup>Johanna K. Lake et al., "The Wellbeing and Mental Health Care Experiences of Adults with Intellectual and Developmental Disabilities during COVID-19," *Journal of Mental Health Research in Intellectual Disabilities* 14, no. 3 (March 14, 2021): pp. 285-300, <https://doi.org/10.1080/19315864.2021.1892890>. Min Ah Kim et al., "Changes in Life Experiences of Adults with Intellectual Disabilities in the COVID-19 Pandemics in South Korea," *Disability and Health Journal* 14, no. 4 (October 2021): pp. 1-9, <https://doi.org/10.1016/j.dhjo.2021.101120>.



community. We also found very limited research that centered on people with ID who live in group homes, and even less research that took their voices into account. We interviewed six individuals on Zoom. After we interviewed them over Zoom, we all came together in a focus group discussion so we could share what we learned and get their feedback.

We wanted to learn about what the COVID-19 pandemic experiences of persons with ID living in group homes were like, and how they might be similar to or different from the experiences of other persons with ID that researchers have talked to. We also wanted to reflect on how their experiences might be similar to, or different from, our own experiences as two people with ID who do not live in group homes.

Together with our colleagues at HPOD and MASS, we brainstormed a list of questions that we put together in an interview guide (Appendix 1) based on what we learned from our review of the research literature. Our questions focused on the following, how the pandemic affected overall wellbeing, health, social supports, their daily routine and how readily available information was. We also looked at lessons learned from the pandemic and how people plan to move forward. An example of one of our questions was “Were any big decisions about you that were made without you during the pandemic?”<sup>8</sup>. We used these questions as probes to supplement the list of questions that our colleagues at HPOD had originally developed.

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<sup>8</sup> For the full list of interview questions see appendix 1 below.

Ahead of our interviews, we worked on individual blog posts that helped us prepare ourselves mentally for the interviews. [Diana's post about how to have conversations with persons with disabilities](#) contains good tips for helping people with disabilities to open up. [Tony's post about his experiences trying to live independently during the COVID-19 pandemic](#) were a useful reminder for the kinds of barriers that persons with ID not living on their own may face.

During the interviews, we did not just read off a script. Instead, we tried to have a natural conversation. Some of us spoke more during certain parts of the interview than others, and we worked together with our colleagues at HPOD as a team. Every interview ended up being a little bit different. Where some of the interviewees seemed like they needed help or encouragement, we did so, because at the end of the day, we're not just researchers, we're self-advocates.

After our interviews, we met with our HPOD and MASS colleagues to discuss what we heard. We made notes of our discussions and used those notes as part of this report. Anne Fracht (Self-Advocacy Associate, Harvard Project on Disability) and Hezzy Smith (Director of Advocacy Initiatives, Harvard Project on Disability) helped us with writing down our discussions and making this report. We reviewed what they wrote and suggested changes where we thought appropriate.

Two interviewees that we spoke with had been previously interviewed before our fellowship period began. For these two interviewees, we watched recordings of those interviews. We also participated in a follow-up interview with Interviewee #1 in August 2022. Finally, we did a follow-up interview with Interviewee #4 because his Wi-Fi connection was unstable.

We helped to facilitate a focus group discussion over Zoom with all six interviewees, where we shared what we learned from the interviews and invited the interviewees to give us feedback and to fill in gaps in some of what we learned. Together with our colleagues at HPOD and MASS, we brainstormed questions that we wanted to ask our interviewees and used those to guide the discussion. We arranged a follow-up interview with Interviewee #3 after the focus group discussion, because although she was listening in, she was unable to participate due to background noise.

## **ISSUE, EVIDENCE & KEY FINDINGS**

We used Zoom to remotely interview six persons with ID who have been living in group homes in Massachusetts throughout the COVID-19 pandemic. HPOD had obtained a written exemption determination from the Harvard Law School's human subjects research officer before recruiting interviewees.

### ***How We Recruited the Six Interviewees***

HPOD worked with MASS to identify and then recruit eligible interviewees. To be eligible, interviewees had to be adults who identified as having an

intellectual or developmental disability, were legally authorized to consent to participate on their own behalf, and had lived in a group home in Massachusetts for at least six months since the start of the COVID-19 pandemic, in spring 2020.

Interviewees were compensated with \$50 Amazon gift cards for participating in both an individual interview and a focus group discussion, paid for by HPOD after the focus group discussion was completed. HPOD determined whether prospective participants met the eligibility criteria for the study and then scheduled a time for the interview.

It was more difficult than we expected to recruit interviewees. We thought a lot of people living in group homes would be interested in sharing their stories. HPOD and MASS shared a recruitment flyer with many service provider agencies, service coordinators, and individuals they knew.

Although we had to exclude some prospective participants because they had full legal guardians, we were surprised that recruitment was so challenging. For example, even though recruitment flyers were sent to a number of service coordinators and agencies that operate group homes, none of our interviewees came from these sources.

### ***About the Six Interviewees***

Our interviewees ranged in age from 32 to 54 years old. Three of our interviewees were female, the other three were male. Five of them identified as

white or Caucasian, while one identified as Latina or Puerto Rican. Four used power wheelchairs to get around. Four interviewees had caught COVID-19 once during the pandemic, while two reported never having it. None of them used assistive technology to communicate, although one interviewee relied on staff to help interpret his speech.

The size of their homes ranged from 4 to 6 people, although one interviewee's home was a part of a duplex, where 8 people in total lived. They all had their own bedrooms. They had been living in their current group homes from 1.5 to 22 years. Although two of them had switched group homes during the COVID-19 pandemic, they had all lived in group homes several years before the pandemic began—one of them since he was 9 years old. One interviewee had also previously lived in an institution.

One interviewee had a guardian, but only for medical decisions, and she was authorized to consent to her participation in our research. Two other interviewees had a health care proxy. For four interviewees, their group homes were their representative payees, while two did not have representative payees<sup>9</sup>.

All six interviewees identified as “self-advocates,” which means they advocate for the rights of persons with intellectual disabilities, and were

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<sup>9</sup> A representative payee is someone who manages Social Security Benefits or Supplemental Security Income on behalf of beneficiaries who may be unable to manage their own payments or need additional support. This is often a family member or friend but can be a trustworthy organization.

involved with MASS to varying degrees. All were active participants in MASS regional self-advocacy groups. Three of the interviewees were trainers through MASS’s [Awareness & Action](#) or [Self-Advocacy Leadership Series](#) programs. One of the interviewees currently serves on MASS’s board.

The table below includes some background information about our interviewees:

<b>Interviewee</b>	<b>#1</b>	<b>#2</b>	<b>#3</b>	<b>#4</b>	<b>#5</b>	<b>#6</b>
<b>Gender</b>	Female	Male	Female	Male	Male	Female
<b>Race</b>	Latina	White	White	White	White	White
<b>Region</b>	Northeast	Northeast	West	Northeast	Central	Southeast
<b>Housemates</b>	5	4	3	4	4	3/7*
<b>Age</b>	37	54	32	37	52	53
<b>Years in Current Home</b>	1.5**	3	2.25**	3	22	8
<b>Total Years in Group Homes</b>	15	11	17	29	22	8
<b>Wheelchair User</b>	Yes	Yes	No	No	Yes	Yes
<b>COVID</b>	No	Yes	No	Yes	Yes	Yes
<b>Interview Date</b>	Dec. 7, 2021	Mar. 1, 2022	July 11, 2022	July 25, 2022	Aug. 5, 2022	Aug. 8, 2022
<b>Follow-up</b>	Aug. 8, 2022	N/A	Aug. 19, 2022	Aug. 10, 2022	N/A	N/A

\* Indicates an interviewee has 3 housemates in her unit but 7 more housemates if counting both units in her duplex.

\*\* Indicates an interviewee moved into a new group home after the pandemic started.

Below, we describe the six interviewees’ pandemic experiences:

## ***Interviewee #1***

Interviewee #1 has a number of medical issues that have made her especially cautious during the COVID-19 pandemic. There are some periods where her health declines and she has frequent hospital visits. Her health issues “stop me from going out or seeing more than just one person. I can’t be in a group of people, because they say some people feel symptoms and others don’t.”

Staffing shortages were another barrier. If staff doesn’t come into work, then sometimes she has to postpone her trips into the community. “I can’t go on the ride yet on my own,” and so relies on the house van for transportation over longer distances. But there always needs to be staff at home because two of her housemates are older and don’t go out at all. “I wish I could go places. Staying home isn’t fun at all. ... I’m sick and tired of working at home.” She also has not been able to go out as often on the weekends or outside of her Zoom trainings. “We’re short of staff because of the pandemic, so we’re dealing with that.” But she says, “There’s nothing you can do. You have to adapt to things and change your mentality.”

Now, she gets out once in a while for appointments, “but not too often because I’m protecting my housemates. ... If my housemate weren’t sick I’d go out more often.” As a result, “I have to stay out a shorter amount of time. I can go to the bank and [have] something to eat but then come back home.” She says to use the van, they need at least three people, which means it’s only

rarely that she leaves the house for longer periods. Although visitors are allowed so long as they test negative for COVID-19 and wear a mask, she didn't report having many visitors.

She used to live in a group home that had one floor with a group of housemates who had behavioral issues. These behaviors increased during the pandemic. While she was trying to work remotely as a trainer, both for MASS and for the Department of Public Health during the pandemic, she found it increasingly difficult to stay in the same house. Her housemates' behaviors worsened, and eventually, it felt like there was "chaos." Staff would frequently apply restraints to her housemates.

So, in February 2021, she changed her living situation. She now lives in a different group home that has two floors. She lives in the in-law apartment in the basement level of her home, where she has a half kitchen and more privacy. Her housemates are also older, and although they have greater medical needs than her previous housemates, they are quieter. She also finds that the staff in her current group home are more responsive. Whereas in her previous group home she would have to ring her buzzer to call a nurse 4 times before she got a response, in her current home, she says that staff come right away.

Although in the last seven months the house has had seven different COVID-19 exposures, she generally feels safe in her living environment. "I



know I'm protected." She says, "Nursing was on top of the exposures. Not just this house, but in other houses in the same agency, the staff on top of it, taking temps, making sure none of us was sick, that's why I like living here." Her staff "clean and clean and clean." When they pass around people's mail, they wear gloves. In addition to masks, they wear other protective equipment, like gowns. "They look like surgeons," she tells them. "You have to laugh if you have to deal with COVID."

She has not had COVID-19 even though her housemates and staff have. When her housemates aren't isolating due to an exposure, she generally goes upstairs to eat her meals. Even though she has a half-kitchen in her apartment, "I got to go upstairs, because if I choke then they're liable." At meals, "We try to eat while social distancing, but what can you do? We eat at the same table."

She recalls at least one close call, though. Earlier in the pandemic, at her previous group home, one of her staff came into work with COVID-19 symptoms. She noticed these symptoms and told her staff that he probably has COVID-19, but her staff insisted that he did not. The staff proceeded with his duties to help Interviewee #1 with getting dressed and eating breakfast. The next day, however, he tested positive for COVID-19 and did not come into work until her quarantine period had ended. Luckily, Interviewee #1 did not test positive despite her exposure. Interestingly, she did not feel angry or frustrated

that the staff came into work despite having COVID-19 symptoms. She is just grateful that she did not catch it herself.

She reported at least one silver lining. She takes several daily medications to help with her health issues. Before the pandemic she had been transitioning towards self-medicating, a process that was put on pause when the pandemic first started. But since moving to her new group home, she has resumed that transition process, and she now takes her 4 o'clock medications independently, which is a source of pride.

### ***Interviewee #2***

For Interviewee #2, the pandemic has been “disappointing.” It has also made him “mad.” “It was hard for me. I can’t go out. ... I can’t go to Wal-Mart, the movies, to my peer group meetings, or dancing. ... And I can’t see people.” For that reason, all the meetings he’s had with people have been outside. Part of the reason has been that he cannot wear a mask: it doesn’t stay on his face properly. As for face shields, he said, “They [his staff] can’t find them.” Without that protection, he would have been at even greater risk of getting COVID-19. The pandemic has also been difficult because his wheelchair has been broken. He has been waiting a long time—more than eight months—to get a new one. “My chair’s not comfortable,” which has only compounded the pandemic’s difficulties.

He has also feared getting COVID-19 himself since the pandemic started. “I was worried about me, and the other people” in his house, because he saw his home’s staff frequently get sick with COVID-19. He eventually contracted COVID in August 2021, but fortunately he wasn’t hospitalized. “I ached all over,” much worse than a typical flu. He isolated in his room until he recovered. He suspects he got it from people at his day program, not from staff at his group home, however. He pointed to the fact that his housemates also had COVID, but not at the same time as him.

When we interviewed him in March 2022, he had been vaccinated and received a booster shot. “It felt like a miracle.” From then on, he was able to leave the house again. He was able to go dancing again, and eventually to return to his day program.

His day program had closed in the early days of the pandemic and reopened in the spring of 2021. While it was closed, life was “boring.” He “really wanted to go back” a lot sooner than he did. Because the day program was short on staff, the day program didn’t allow him to go back right away when others did. Instead, he had to wait at least six months. He believes that the day program didn’t want him back right away because he can’t walk, and it would be more difficult for the short-staffed program to accommodate him. He let his service coordinator know he was unhappy with this decision; nevertheless, he had to wait until the day program was able to hire more staff.

He has four brothers that he hasn't seen much of during the pandemic. He's especially close with two of them. They used to meet with him in person often, but not since the pandemic started. They've also kept in touch over Zoom, "but it's not the same. It makes me sad." One of the brothers he's close to lives nearby but the other lives in Arizona. He hadn't seen his brother since his birthday six months prior in September 2021. He said he had to advocate with his group home staff so that he could go out to celebrate. "It made me happy."

Unlike other interviewees, who were alone in their rooms during their interviews, staff from Interviewee #2's group home was present during parts of the interview. They helped to interpret his speech at times when it was unclear to us, but they participated only intermittently. We can only imagine how Interviewee #2's communication barriers may have exacerbated his feelings of frustration, boredom, and isolation, in addition to making it more challenging for him to advocate to do the things and see the people he wanted to during the pandemic.

### ***Interviewee #3***

In the early days of the COVID-19 pandemic, Interviewee #3 followed the news closely. "I watched the news, and I was learning from the news because I was on that [keeping up to date]. I told my mom that I watch the news a lot." She also had many conversations with her mother about COVID-19. She urged her

mother to take precautions, like wearing a mask and not going out as much. “I’d be like, ‘Mom, don’t go out. I’ll go out for you. I will go do stuff for you, because of your diabetes, that you can get COVID or pneumonia or get both and you could die from it, Mom.’” But her mother didn’t believe in COVID-19. “I was like, ‘I know if you get it, you are going to go.’ And she was like, ‘No, I won’t. I’ll be here, I won’t catch it.’” But in late March 2020, “she caught it.”

*“Since I was watching the news, I already knew that I was going to lose her. ... You know, she just didn’t believe in it. She didn’t. She didn’t ever really believe in that kind of thing. She never thought you would get sick or that she could get sick from that kind of thing, and she didn’t think it was true. ... She was a stubborn person.”*

After catching COVID-19, her mother was hospitalized, intubated, and she passed away on April 5th. She was able to visit her mother in the hospital and was there with her when she passed away.

*“I saw her on the ventilator. I saw the machine going and everything. Every time my brother and sister or the doctor came in she would go crazy, but when I would talk to her, touch her, or talk to her the machine would stop and just relax and she would know I was there.”*

Before her mother passed away, Interviewee #3 discussed with her mother several times whether or not she should leave her group home and move in with her during the pandemic. Ultimately, Interviewee #3 decided to stay put. She regrets that decision, however, because she feels that if she had moved in with her mother, she could have gone grocery shopping for her and possibly prevented her from getting COVID-19. If she could start the pandemic all over,

*“I would be there with her to help her and probably stay over at her house for a little while to see if I can help her and make sure she wouldn't have caught COVID and help her be able to go out. ... I should have gone with my gut in the first place, because I was going to do that, I was going to leave and go to her house and spend time with her, and I should have because I had a feeling this was going to happen. I should have listened to my gut feeling and not listened to what she told me.”*

Her mother was her biggest supporter. “She's the one that supported me through everything I did for self-advocacy, so it was really hard for me, because she was like my rock.” She experienced some dark moments after her mother passed away. She even thought about suicide. But that didn't stop her from picking herself back up and getting her life on track.

When the pandemic started, Interviewee #3 was living in a group home with three other housemates. But she didn't feel safe living there. Having seen her mom die from COVID-19 firsthand, she was careful to wear a mask in her house when leaving her room. Still, “it was like everybody else [in her home] wouldn't wear their masks.” She explained, “They all didn't believe in COVID because they kept on thinking that Trump was right, that it was just a hoax. So, everybody thought it was a hoax in my group, except for me.” This disconnect distressed her deeply. When she was losing her mother,

*“I told them that and then all of a sudden everybody didn't care to the point that it hurt me so bad that I decided to take my life one night after my mom died. I didn't have somebody to listen or support me through it, so I ended up taking a knife and trying to kill myself with it, because nobody would listen to me, and no one would support me through the rough time that was happening.”*

She also had to eat meals together with her housemates during the pandemic, but they did not practice social distancing at the dinner table. This made her very uncomfortable, especially after seeing her mother pass away from COVID-19.

*“It was kind of hard for me because I had just lost my mom. So, I didn't want to eat with them because I was afraid I would catch COVID, and because of my seizures and I have other things that are wrong with me. So, it was kind of scary for me because I just lost a parent from it, so I was very cautious on what I was doing and where. ... I tried to stay away from everyone else at the table.”*

When she asked the staff if she could eat separately from her housemates, “they said that since we're a group, we had to eat together.” Staff failed to support this individual and in a plethora of ways disregarded her comfort and safety to force socialization. This in turn created more isolation and feelings of loneliness for Interviewee #3.

Another thing that made Interviewee #3 uncomfortable was her home's cleaning protocols. She would often go out on her own for walks in her community, and when she came back, the staff made her change her clothes and shower. It was “frustrating” to her that she had to do these things, but the staff did not make her other housemates do them when they came back to the house after going out. It felt like the staff was picking on her.

In that home, eventually “some of [her housemates] got sick and got COVID and then the whole group ended up with it before I moved—we all caught it together.” The staff came into work with symptoms.

*“That’s how the other girls caught it. The staff was coming with COVID, they were coughing and everything, and then the girls got sick. We had a cat, Sophie, and she caught COVID from the staff, too, and she passed away.”*

When asked how she knew the staff had COVID, she replied, “They told us!” That includes the house manager, whom she called the “top dog”. Generally, five staff persons came to her house each day. Three of them had symptoms. Three times, she called her house manager’s boss, who “had to tell the staff to leave.”

In May 2020, she moved into another home managed by the same agency, where she has more freedom and privacy. Her negative experiences in the group home during the pandemic seemed to influence her decision to live more independently.

*“It was like my dream came true because I had wanted to be on my own, I had wanted to be independent, and I had wanted my mom to be able to see that: me being able to be on my own and being independent and maybe being able to cook for her for like for Christmas or her birthday or the holidays like I did before. But once I moved she wasn't around, so it was really hard because I've met my goal that I always wanted for both me and her, but she wasn't here to see that goal reached.”*

Throughout the pandemic, she felt her goals on her services plan “weren’t being met. Because I had certain goals that I was supposed to be working on during the pandemic, but it felt like they didn't want to help me achieve those goals.” Before the pandemic started,

*“One of my goals was to learn how to manage my money on my own, and also learn how to write checks, because I don't know how to write checks very well. And I still don't know how to write checks. ... I would ask for help and I felt like*



*they were more focused on the other clients in the house, and then the program then focused on what other people in the program needed.”*

Interviewee #3 faced few restrictions on leaving her house and accessing the community. “We could go grocery shopping and go places and do things that we could do.” She added, “The staff take me out into the community. They come, check out, and then they take me out, and they bring me shopping or take me to the park or wherever I want to go.” She also had visitors, including friends of her mother.

*“They took me out for my birthday and stuff during it and after mom died. They were very supportive and coming to see me. ... For Christmas this past year they both came and saw me and brought me a popcorn that my mom would buy me for Christmas.”*

Despite the lack of restrictions on leaving her house, Interviewee #3’s day program was cancelled in the early days of the pandemic. After several months, the program started holding Zoom activities, and she participated in those. But when her program opened its doors again, she decided not to go back.

*“I felt like [the program] didn't fit me because it wasn't [a] good job, and we only had a little bit of jobs. So, it was like where we were just sitting there during the day watching movies or playing games, and that's not my kind of thing. ... I like to be active and I like to work, so I felt like it didn't fit me.”*

Instead, she wants to get a job either caring for animals or baking.

*“I'm a big animal lover, so I'm trying to work with animals, because I used to work when I was in one of my programs. ... I was in an animal care program with abused animals so I'm very dedicated to animals. So, I've been looking at jobs for animal stuff. And I've been thinking ... I want to also do a baking thing, where I have a bakery or something, because I love to bake and cook, or a*

*restaurant that can make Jamaican food, or Spanish food, because I learned how to make that when I was in one of my programs.”*

Even though she hasn't found one yet, she said she wouldn't have decided to look for a job on her own if it weren't for the pandemic.

#### ***Interviewee #4***

Interviewee #4 says that early in the pandemic, his group home staff explained COVID-19 to him when the pandemic started. The staff explained why they have to mask around each other, why they couldn't have visitors, and why they couldn't go out in the community, “because we didn't want to get other people out in the community sick, even if we have hand sanitizer in the house and everybody has to wash their hands. ... I really want to be healthy.” His staff didn't wear gowns, but everyone—himself, his four housemates, and the staff—all wore masks.

Both he and his housemates have had COVID-19 at one point or another. When someone in his home tests positive for COVID-19, the house goes into lockdown. “It gets frustrating being in lockdown, you can't see your family, you can't go out for a ride, on Fridays when we order out, we can't go pick it up, they have to deliver it. It's too much.” Although he's not sure, he thinks that he and his housemates have gotten COVID-19 from either family members who have visited, or the staff, because he and his housemates were inside all the time and didn't go anywhere. Referring to his home's staff, he says “there's usually a lot of people who come in and go out.”

He said, “I feel very safe,” living in his group home. “I have a wonderful house manager who takes care of me. If I get sick, they take care of me.” For example, when he got COVID-19 early in the pandemic,

*“I was scared. He [his house nurse] tested me and one day I came back positive. I had to stay in my room and stay away from my other roommates. I went to the ER. There was so much going on, I was scared and nervous.”*

He was in the hospital for three weeks. During that time, “different staff people came to visit me. They came off and on to bring me clothes to change into. I had a sitter to come be with me. But I was so sick.” He added, “I was having strange thoughts like, ‘I’m not going to be alive any longer.’ I was telling myself that’s not true: ‘I know that I’m not going to pass away.’ I told myself because I was scared and I don’t know what to do.”

When he tested positive for COVID-19 again earlier this summer, although he wasn’t hospitalized, he had to isolate in his room for five days. His staff brought him his meals, and he couldn’t eat with his housemates or use any of his home’s common spaces. “I mostly felt bored. But my foster mom called me and asked if she could bring some books for me to read.”

Interviewee #4 was taken away from his biological parents when he was 9 years old. “My father did bad stuff to me.” For multiple years, he lived at Hogan Regional Center, a state-run institution that now houses over 100 persons with ID. As he tells it, “I have a hard time when I get upset.” He added, “I’ve got so many holes in this room.” He explained that when he behaves in certain ways, like breaking a window or banging furniture in his room, his group

home will put him on a supervision protocol—“not suicide watch but they had to have people watch me”—or take his cell phone away from him for several days. In his words, ““If I do something bad, they take it away for three days, or five days.” He’s also not allowed to use the house phone when he’s “on restriction.” Even though he had bought his cell phone with his own money and he pays his phone bills, he doesn’t view these restrictions as unfair. These rules, he said, are written into his service planning documents.

He said he has been having negative feelings more frequently during the pandemic. For example, in June 2022, “I did something bad and my staff took my phone away.” He explained, “I called the police on it. The police and the ambulance started to come because I was hurting myself.” He had banged his hand on the wardrobe out of frustration, “because, at that moment, I was talking to my girlfriend, and she was telling me that another guy was trying to go out with her, but she said that wasn’t the case.” He had

*“...locked the door to my room. The staff came in and said, ‘[Name], what the heck are you doing?’ I said, ‘It’s none of your business.’ So, he took my phone away from me and chucked it out of the room. And I was laying on my bed and the police showed up and I was like, ‘Oh my God I’m in trouble.’ They took me to the hospital because they thought I might have fractured my hand.”*

Interviewee #4 has had two part-time jobs for over a decade working for his foster parents. One was at his foster father’s warehouse, the other at his foster mother’s event planning company. While his foster father’s warehouse reopened last year, his foster mother’s company remains closed. At the warehouse, he’s an assistant manager and operates a manual forklift. “It’s a lot

of work.” At the event planning company, he’s a doorman manager. He was “frustrated” that he couldn’t go to work for more than a year after the pandemic started. The warehouse reopened last year, and his foster mom called him to ask if he could start working again a few hours a week. “The group home let me go no problem. They dropped me off, they picked me up,” although they recently asked him to start using paratransit to get to work, as he used to do before the pandemic. He hopes his foster mother’s company will reopen in September 2022.

He likes both his jobs though he sometimes struggles to meet expectations. He says he would like to work more hours, but his job is a long trip away. Now, he says,

*“I’m trying my best to not get into trouble like I did yesterday. I was at my foster dad’s yesterday and I got a talking to and it wasn’t good. What happened was, when I got there I went to check to see where my manager was and I was sitting down next to [the] trailer, and he comes out of the warehouse and he said, ‘You should come in and look for me.’ I told him I went to the bathroom and I forgot to tell him I was going to lunch and that I’d be back in 15 minutes. Right now I’m afraid I’ll be suspended.”*

He lost his biological mother to cancer towards the outset of the pandemic. “She got very sick. They couldn’t do anything for her.” He hasn’t been allowed to have contact with her since he was separated from her when he was 9 years old, he explains, “because I have a hard time being with my mom.” But he still felt close to her and found her loss painful. “It was hard. I went to the wake and everything. It gave me more sad and angry feelings.”

One of the bright spots of the pandemic has been his new romantic relationship. “She makes me feel so good. She makes me laugh every day. Oh my God, she’s one of the happiest women I’ve ever met in my whole life. She’s unbelievable, and she loves me so, so much. I’m glad that I’m with her.” Although a mutual friend had introduced them before the pandemic, they began dating in June 2022. But he says it’s been challenging to date during the pandemic, even during these past few months.

*“It’s hard because if my roommates have visitors come over, or if someone has COVID, then the house will be in lockdown. If we’re in lockdown we’re not allowed to go out or have visitors, and we have to stay in our rooms for 5 days. We haven’t been in lockdown for a couple months now. But it makes her very upset. I know she loves me very much and I love her very much.”*

She lives in another group home in a nearby town. “They have lockdowns, too. They’re kind of like my house: they don’t have lockdowns right now. She wants me to go to her house to play a game or something.” For now, at least, “We don’t get alone time when we visit. She is only allowed to visit for a half an hour. ... I think that’s fair. Right now we’re just learning [from] each other.”

#### ***Interviewee #5***

In the early days, Interviewee #5 was very isolated. He spent a lot of time in his room. He even took meals in his room by himself. “There were times we had to stay in our rooms. It was kind of tough back then because [the staff] would have to put gowns on to come into anybody’s rooms.” He added, “I’m a person who likes to be around people. To be told you’ve got to eat in your room, sleep

in your room, stay in your room is tough. But with the staff we have, I wouldn't change a thing." Staff would occasionally catch COVID-19, but they would stay away from work until they were cleared to return. He hasn't been concerned or worried about the risk of catching COVID-19 from staff. "They take tests, and as long as I don't have it, I'm okay."

Interviewee #5 lives on a dead-end street and sometimes goes out for a stroll around the block, "down to the bakery and back." For anything farther, he generally uses the group home's van to get around. However, he has to plan those trips at least two weeks ahead of time, which prevents him from attending any events without advance notice. But he says, he "wouldn't change a thing" about his group home. "I always say, when [others] ask me, my staff here is super. They're top notch. I moved in on June 16, 2000, and I wouldn't change a thing."

Interviewee #5 had one staff person he was very close with who "decided not to come back" due to the pandemic. Although he had worked with her for a long time, he said, "That was her choice. There's nothing I can do about it. It took some getting used to but now I'm over it." He added, "I don't think it was the right choice to make because it affects all of us, but that was her choice." He continued, "She didn't want to take the precautions, so the agency let her go." He supposes that she didn't believe in COVID-19, but he's unsure about her thinking because they never got a chance to talk about it. One day, "she just didn't show. And just last week the nurse called up to say

she was taking medical retirement without saying goodbye to us.” This isn’t normal: in his experience, staff usually say goodbye before leaving. But she didn’t say goodbye, which was painful for him.

Interviewee #5 used to attend a day program, but that closed in the early days of the pandemic. The day program transitioned to offering online meetings, “but it wasn’t the same. I stopped going through the iPad. That’s why I want to do more work with MASS,” as a trainer, “and try to get involved more.” At the day program, “all we would do was wait around and wait for them to decide what they would have us do.” When asked why he didn’t make that change earlier, at some point before the COVID-19 pandemic, he explained: “I didn’t want to see it, but my [house] manager—she’s a good manager—said to me, ‘Why don’t you work from home?’ And I said, ‘You know? You’re right!’”

Throughout the pandemic, Interviewee #5 was able to have visitors. His house’s policy, however, was for people to speak to visitors through the screen in the kitchen door. Although he typically sees his cousins and other extended family members more frequently, he has only seen his mother and his aunt and uncle during the pandemic. He especially looks forward to his mother’s visits: she comes every other Saturday and they go out to Dunkin’ Donuts for coffee.

One of the bright spots of the pandemic for Interviewee #5 has been a Bible study group, which he joined through a person at MASS who introduced him to it. He also started attending 11am services at a nearby Baptist church,



regularly, by Zoom. He says the pandemic has prompted him to become more religious and to explore his spirituality. Before the pandemic, he used to only attend services occasionally, like for religious holidays. “It makes me feel good. They give me the chance to be with God and they give me the chance to study what’s in the Bible.”

### ***Interviewee #6***

For Interviewee #6, the pandemic has meant not even stepping outside her home.

*“When COVID came, we couldn’t go nowhere. I stayed at home for two years. We couldn’t go anywhere for two years. ... I’ve had to stay in the house for two years. Everything was shut down. No trips, and no people can come over. ... They shut everything down.”*

Even now, to make a visit, “You have to call and make an appointment.” And still, just to go outside for a stroll in the neighborhood, “You have to schedule everything. It’s not good for me because you have to have staff fully booked. If they don’t have staff, we can’t go out.” When she tries to go out, “The staff say, ‘We are busy people.’ I live with four people and I have to get them to agree. We have to go out together if we go out. It’s very difficult to go out. I used to live on my own.” She continued, “It’s very hard to live in a group home, believe me. ... Believe me, I want to get out of here as soon as possible. But I can’t find a place to live because of my chair. They don’t have no houses for me yet.”

Interviewee #6 lives with seven other housemates: three in her unit, four in her duplex's adjoining unit. "But they don't speak," which makes her opportunities for interacting with them limited. She says she wasn't even allowed to have window visitors. "The agency is very strict." Although her group home, like others in the state, arranged for car parades, her agency "did that for a while but then they stopped." To go out to get something to eat on her own, for example, "I have to have staff with me. I don't like it, but it's the rule of the agency. I've talked about this with a lot of people," but she hasn't been able to change these rules. When asked what would happen if she broke those rules, she replied, "We get in trouble if we go anywhere. They call the cops." It hasn't happened before, "but that's what they told me. It's the agency rule." She added, "This agency is very strict. If you don't do what they say, you'll get in trouble. They'll get the big boss to come and talk to you."

*"I'm only here because I have to be. I lived on my own for twenty years, but my PCAs [personal care assistants] took off on me. The agency said, 'We have to put you in a group home.' I didn't have a choice. I was forced to come here. I had two kitties I had to give away. I don't want to be here, but I have to be here. I've tried everything, but nothing works so far. I've called the hotline and they tried to help me, but they can't find me nowhere. So, I have to stay here. Believe me, I'd rather be somewhere else. I want my life back. This is no life for me."*

Only one of her housemates has caught COVID-19, but Interviewee #6 did not catch it. "I was very careful. I just stayed in my room. I lost my mother to COVID." It was early in the pandemic, she was hospitalized, had an operation, and when she recovered a little, "then she was transferred to a

nursing home, and she got COVID in there.” Interviewee #6 wasn’t able to visit her mother while she was in the nursing home. She didn’t have a chance to say goodbye. “I miss her every day.” Her father also passed away from cancer a few months earlier. She wasn’t able to say goodbye to him in person, because he lives in Florida, but she was able to say goodbye over Zoom. “I was very close to both of them.” She was able to go to both her mother’s and her father’s funeral services, which her sister put together.

Now, her sister is her closest family. She last visited about three weeks before our interview. Interviewee #6 hasn’t seen much of her sister recently because she is busy wrapping up her parents’ affairs. “This is why I’m trying to move out of here. I want to do more but I can’t. It’s a pain in the ass. But my sister wants me to stay here.” Her sister is her health care proxy, but she has no legal authority to make decisions on Interviewee #6’s behalf. “I’ve talked to a lot of people but they say, ‘I’m sorry. We can’t find anything for you.’ What can I do? I’ve tried everything but nothing works.” We gave her some advice about who she might contact to support her advocacy to move out of her group home, and offered to follow up with her after the interview.

Interviewee #6 switched day programs in January 2022. Her previous day program kept opening and closing because people would catch COVID-19. Her current day program has been more consistent. Nevertheless, just before the interview, she had recovered from a case of COVID-19 that she believes she caught from her new day program. She likes her new program

better: “The people are very nice.” She had been thinking of changing her program before the pandemic, but she seized the opportunity to make this change. Her previous program was “boring. We just watched TV.” She had gone to the previous program for seven years, and she liked the staff and the other participants, but because “staff would always call in sick” after it reopened during the pandemic, they just watched TV.

She had just gotten over a case of COVID-19 at the time of interview. “It was really scary.” She believes she caught it from her day program. “Five people had it at [her day program] before me. I got it from [there].” At the day program, “they told us to wear a mask on a Friday,” but “they didn’t say anything” to explain why. She figured that people had caught COVID, but she was told this information only later, after she had gotten sick. “Then on Monday I took the test when I got home.” In her opinion, “They [the day program] should have told us. They kept it a secret because of privacy, but we have to know.” She feels her day program put her in danger. “They’re supposed to tell us if someone gets sick. ... If I knew that they tested positive I wouldn’t go.”

She also feels that her group home was responsible. On the Monday morning after she noticed everyone had to wear masks, she told her group home staff that she didn’t want to go to the day program, because she was scared of catching it. “I never had it before, so I didn’t know what to expect. Because of my CP [cerebral palsy] I can get very sick. I didn’t know what would happen to me.”

But her group home staff made her go to her day program anyway. “Because they want everyone to go to [the] program. On Monday the group home doesn’t have staff. They only have two people. Mondays are difficult.” If she wants to stay home, “I have to tell them one week in advance because they have to hire extra staff. It costs them a thousand dollars a day,” if she stays home. “The big boss told me so. One day I asked him. He said, ‘If you want to stay home you have to pay.’ That’s what he told me.”

When asked if she called her human rights officer about this, she answered, “No, because it’s not worth it. ... One day I called the DPPC [Disabled Persons Protection Commission] on the agency, because it’s not fair. It’s the only way I know how to fix it.” But her group home staff told her, “You can’t do that because you’ll get other people in trouble.” In her view, “It can’t get even worse than this. I hate this place. ... The only way I can get out of here is if I call a lawyer.”

Beyond her day program, Interviewee #6 also has a job. She is an Action and Awareness trainer for MASS, where “I talk about abuse to people. I like it very much. I’ve been doing it for six years now and they’ve told me that I do a very good job.” She added, “I like to help people.”

### ***Focus Group Discussion***

After all individual interviews were concluded, HPOD organized a focus group discussion on August 15, 2022, with all the interviewees to share our findings

with them and to get their feedback. We wanted to know what they thought could be done in the future to better support, and give autonomy to people living in Group Homes .

We prepared PowerPoint slides to guide the focus group discussion, which are attached at the end of our report in appendix 2. At the discussion, we presented several themes, which we divided into two broad groups, reflecting positive aspects of interviewees' pandemic experiences as they relate to social connectedness, and the negative aspects of the pandemic. Among the positive aspects of interviewees' experiences, we identified the following:

- Some people strengthened their relationships or formed important new ones.
- Some people changed where they lived for the better.
- Some people made positive changes about the work they do.
- Some people got more access to technology.

Among the negative aspects, we identified the following themes:

- Everyone felt frustration, isolation, and boredom at various stages.
- Some people seemed to face avoidable risks of getting COVID-19.

- Some people lost loved ones to COVID-19 or staff they were close to left.
- Some people didn't have a lot of control about leaving their houses due to staffing or transportation.

We also discussed the different kinds of information that interviewees reported receiving about COVID-19. Most interviewees reported, for example, receiving information from their group home staff about COVID-19, and explanations about precautions they had to take, such as wearing masks and social distancing. But it seemed that interviewees did not receive much information about the special kinds of risks that people living in group settings have faced during the COVID-19 pandemic, such as the risk of catching COVID-19 from staff.

We received interviewees' feedback and reactions to these themes in a semi-structured group discussion with all interviewees after we presented these themes. The participants largely agreed with the themes that we presented. Some themes were emphasized more in the group discussion than came through in the interviews. For example, Interviewees #1 and #4 affirmed during the group discussion that staffing shortages in their homes had a big impact on their ability to go out, even though they did not make this connection as clearly during their interviews.

Some new themes emerged during this discussion that did not come through during the interviews. One important theme was that group home staff did not seem to make efforts to foster social connectedness inside the homes, especially during periods of lockdown or isolation. In the focus group discussion, interviewees suggested that while their group home staff focused on residents' physical safety and well-being, they did not do much to promote their mental health. Interviewee #2 was adamant that group homes could have done more to "work with people to stay busy" and have greater access to visitors during the pandemic.

Another important theme was access to information during the pandemic. Beyond the specific experience of Interviewee #6 with regard to her day program withholding information about COVID-19 transmission, during the focus group discussion, other interviewees agreed with the lack of information they sometimes had throughout the pandemic. For example, Interviewee #5 reflected, "I find some staff to be more honest and some people can be more withdrawn—withholding information." Interviewees #1 and #2 agreed, with Interviewee #1 adding, "Staff can definitely be more honest."

Also, some themes were unspoken. For example, when interviewees discussed visitors, they generally only spoke of family members, not friends. While several interviewees did start new romantic relationships during the pandemic, it seemed like they generally lacked natural, non-paid supports outside of their family.



Another important theme was the critical role that staff plays in creating positive environments in group homes. In the words of Interviewee #5, “without them, the house wouldn’t be a home.” At the same time, the staff can have negative effects. Indeed, during their interviews, Interviewees #1 and #3 shared examples of staff reporting to work with COVID symptoms and having to be told to go home, while Interviewee #6 shared that she caught COVID-19 recently when her group home staff made her attend a day program where she knew several people had recently tested positive.

## **RECOMMENDATIONS**

Researchers and policy-makers should make sure that they don’t just view people with ID as statistics. They have complex lives and face a plethora of barriers that many people without disabilities don’t realize. This is even more true for people with ID who live in group homes. It’s important that researchers and policy-makers hear their stories and spend time listening to them, so that they can better understand both what they’re going through, and also what needs to be done to support them on their own terms. It is critical to not treat people with ID as a monolithic group but rather to recognize the myriad of experiences that they bring to the decision making process.

Agencies that run group homes should focus their efforts on helping people with ID to choose how to live their lives, not just to keep them safe. Group home staff should not take away people with ID’s lifestyles. Leaving

their house shouldn't be one of the biggest barriers people encounter in their day to day lives. Group homes need to lessen the number of restrictions they have on people going out. If people with ID can't even control where they go, then how are they going to be connected to their communities and fully included in society?

Agencies should also consider more seriously their role in promoting the social connectedness of people living in group homes. It seemed to us that many of the interviewees felt isolated inside their group homes. Their stories suggested **that they were living together, but apart from one another**, in addition to facing barriers to accessing the broader community. Group home staff could probably have done more to find creative ways to facilitate the group home residents' feelings of connectedness, especially during this period of isolation.

Self-advocacy organizations should work to help people living in group homes understand the ways in which their staff may have violated their rights during the pandemic. The pandemic was a whole new world, and many people might not have realized that some of the things that staff did during the pandemic might have affected their rights. Self-advocacy organizations can play an important role to help people living in group homes better understand what things their staff did are okay, what things are not okay, and what things they should have been doing but weren't.

## IMPACT

The Social Connectedness Fellowship has affected both of us in important ways and made us reflect deeply on our roles as self-advocates.

For Diana, learning how to research helped her to appreciate other people's thoughts and stories more. To do research well, you have to be welcoming and open to learning: only then will research lead you to new knowledge. The stories we heard reminded her that everyone struggles fitting into today's society, and that labels and self-worth go hand in hand. It was very complicated for the people we interviewed to live their lives during the pandemic. Some people were limited by their staff. For example, when people were isolating or in lockdown, the staff didn't help them to do things. Instead of inspiring their minds or exploring, their staff focused on the COVID-19 protocols. The staff seemed to see people just as their labels, and they treated them that way. How the staff treated them seemed to affect their mental wellbeing and sense of self-worth. It's hard to advocate for yourself in that kind of situation, especially during a pandemic.

For Tony, the stories we heard made him realize how many different people with disabilities don't know their rights. It's amazing. As self-advocates, we talk about rights in so many different ways, and some people with disabilities don't get it. It boggles my mind that we advocate for different things all the time, but our peers—do they understand what we're advocating for? As self-advocates, we have to take responsibility for speaking up for ourselves,

too. Tony learned this the hard way: he used to live in a group home, too, and he had to advocate to live his life despite all their rules and regulations. Sometimes it's hard to advocate, but you can't give up. Some of the people we interviewed seemed to have given up on some of their rights. It made Tony realize how much more the self-advocacy movement should be doing to support people living in group homes to take responsibility for advocating for their rights, especially when the going gets tough, like it did during the pandemic.

We want our fellowship output to show the research community the importance of involving self-advocates in research about people with disabilities. "Nothing about us without us"<sup>10</sup> applies to research, too. We saw that many researchers who explored the experiences of people with ID during the pandemic did not include the points of view of people living in group homes. Because we are self-advocates, we asked questions differently and live closer experiences to our interviewees. We believe that being self-advocates allowed us to get information that people with ID may not have shared with other researchers. We have also expanded what researchers know about this group of people with ID. The people we interviewed were comfortable talking to us and sharing their stories, many of which were sad or frustrating, because we are self-advocates and we have had similar

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<sup>10</sup> This slogan is commonly used within Disability Rights spaces, amongst many other social movements to advocate for the full inclusion of the affected group in the decision making process. The slogan relies on the principle of full participation and respect for the lived experiences of the community, in this context people with disabilities or disabled people depending on the person's preferred term.

experiences. We treated each person like a person, not like a statistic or a monolith. We want other researchers not only to pay more attention to the lives of people with ID who might face barriers to participating in the community, but also to work with self-advocate researchers like us so that we can help people with ID better tell their stories.

## CONCLUSION

The six persons with ID living in group homes we interviewed reported having numerous experiences that echoed the findings of other researchers who interviewed persons with ID living in other settings, namely, feelings of isolation and frustration related to lack of access to jobs, natural supports, and communities.<sup>11</sup>

At the same time, our research shows that persons with ID living in group homes also experienced the COVID-19 pandemic in different ways. Specifically, they reported lack of access to their communities, lack of access to information about COVID-19 transmission that they needed to keep them safe, and a lack of control over their environments beyond that experienced by persons with ID living independently or with family members. While some interviewees applauded their staff's role in keeping them and their housemates

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<sup>11</sup> Johanna K. Lake et al., "The Wellbeing and Mental Health Care Experiences of Adults with Intellectual and Developmental Disabilities during COVID-19," *Journal of Mental Health Research in Intellectual Disabilities* 14, no. 3 (March 14, 2021): pp. 285-300, <https://doi.org/10.1080/19315864.2021.1892890>.

Min Ah Kim et al., "Changes in Life Experiences of Adults with Intellectual Disabilities in the COVID-19 Pandemics in South Korea," *Disability and Health Journal* 14, no. 4 (October 2021): pp. 1-9, <https://doi.org/10.1016/j.dhjo.2021.101120>.

safe during the pandemic, others observed that staff, at times, added to the difficulties of the pandemic.

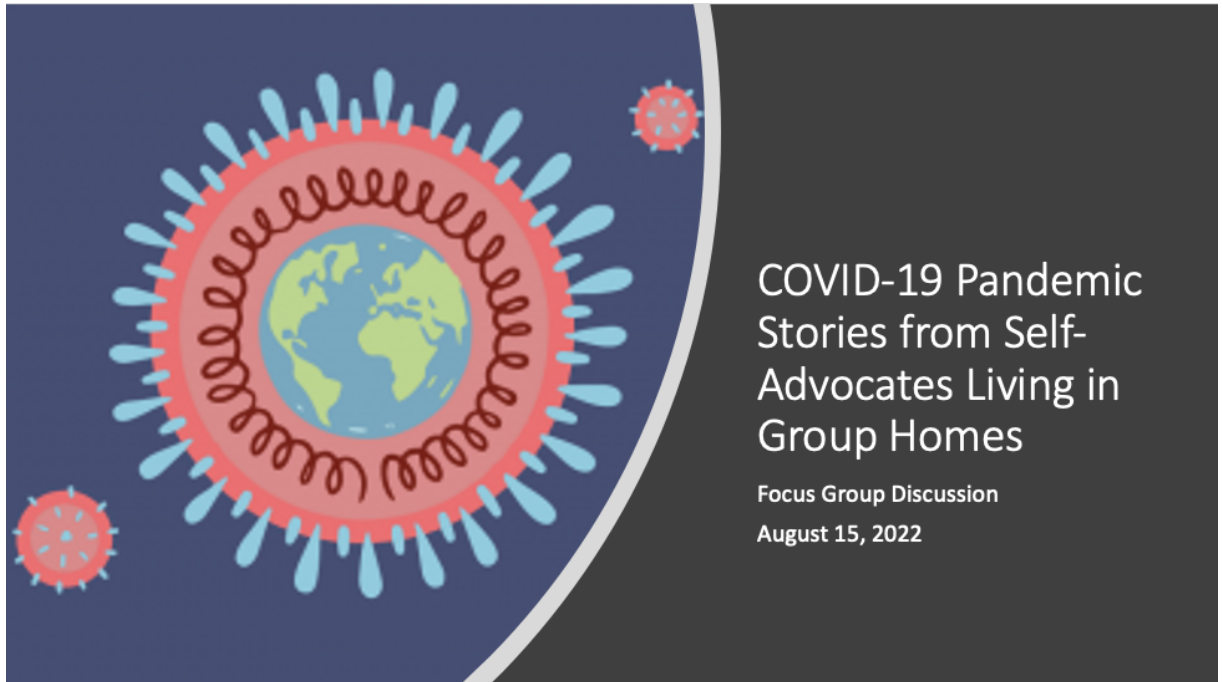
Most importantly, we hope that our research shows that persons with ID can do research on issues that affect persons with ID, and add to our understanding of their experiences. Therefore, we believe that persons with ID, especially those who identify as self-advocates, should be more involved in designing and carrying out this kind of research.

## Appendix 1

1. General Questions
  - a. How has the COVID-19 pandemic affected you?
  - b. What changes happened in your life because of the pandemic and how did you feel about them?
  - c. Is there anything you have struggled with during COVID-19?
  - d. What type of emotions have you gone through during the pandemic?
  - e. Were any big decisions about you that were made without you during the pandemic?
2. Health
  - a. Did you ever get COVID-19? If so, how did it make you feel?
  - b. Did you ever have to isolate yourself (because one of your housemates got COVID-19)?
  - c. Have you felt safe while living in your group home during COVID-19?
3. Information
  - a. Was COVID-19 explained to you so that you could understand it?
  - b. Do you know why you had to wear a mask?
  - c. Do you understand what lockdown is and did someone explain it to you?
  - d. Did you understand why you couldn't go out or have visitors?
  - e. Did someone explain to you about vaccines? Did they explain why you should get one?
4. Daily Routine
  - a. What has your typical day been like during the pandemic?
  - b. What activities or hobbies did you do to keep busy during the pandemic?
  - c. Have you had chances to exercise during the pandemic?
5. Disruptions

- a. Did you have to change your bedroom area?
  - b. Did you have to adjust to a new schedule?
  - c. Have you had to change your meal time?
  - d. Were any of your appointments with doctors or therapists canceled because of the pandemic?
  - e. Did you lose your job or space in a workshop or day program?
  - f. Have you been able to work since the pandemic started?
6. Supports
- a. Have you felt supported during the pandemic?
  - b. Was there a shortage of staff or other people helping you during the pandemic?
  - c. Has your service coordinator been in touch with you at all during the pandemic?
  - d. Have you ever felt like your issues aren't getting addressed during the pandemic? (This could include day-to-day issues, like getting to the grocery store or bullying, or issues with your ISP.)
7. Staying Connected
- a. Have you gotten out in the community during the pandemic?
  - b. Have you been able to communicate with your loved ones or the outside world?
  - c. Have you been able to participate in any activities on Zoom or online?
  - d. Have you had any visitors coming to see you during the pandemic?
  - e. Did you have any conversations with your family about leaving the group home because of the pandemic?
8. Lessons Learned
- a. What would you do differently if you had to do the COVID-19 pandemic all over again?
  - b. What would you have wanted your group home to have done differently?
  - c. Was there anything that you learned about yourself or others during the COVID-19 pandemic?
9. Looking Ahead
- a. What activities or hobbies did you do when everything opened up again?
  - b. What goals did you accomplish since the COVID-19 situation improved?
  - c. What are some goals you would like to accomplish now?

## Appendix 2



### Meeting Agenda



INTROS



QUICK Q'S

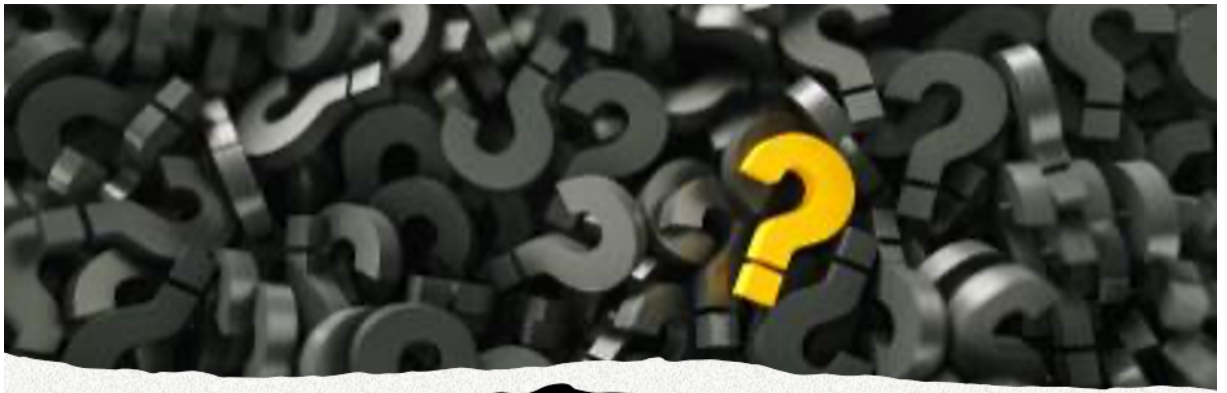


THEMES  
FROM OUR  
INTERVIEWS



GROUP  
DISCUSSION





## Quick Questions



Themes from Our  
Interviews:  
How the COVID-19  
Pandemic Affected Self-  
Advocates Living in Group  
Homes

## Positive Aspects



Some people strengthened relationships



Some people changed where they lived for the better



Some people made positive changes about the work they do



Some people got more access to technology

## Negative Aspects

People felt frustration, isolation, and boredom



People seemed to face avoidable risks of getting COVID-19

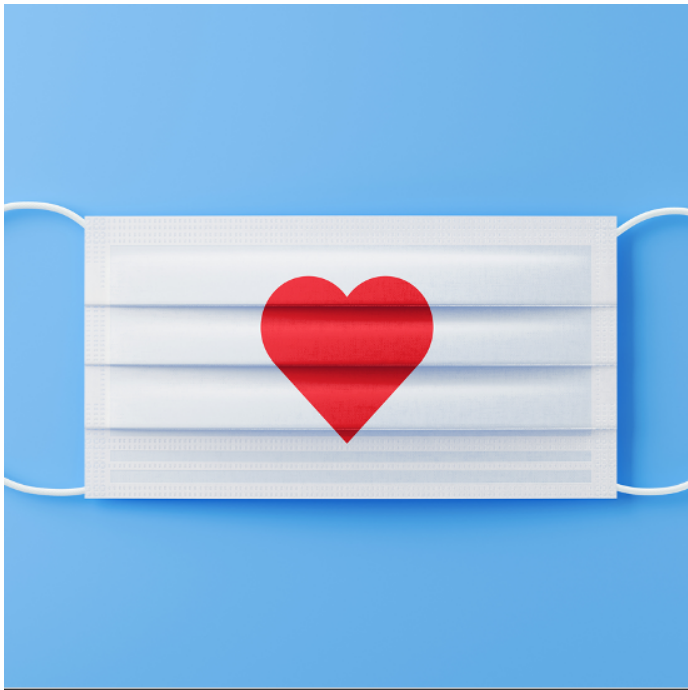


People lost loved ones to COVID-19 or staff they were close to



People didn't have a lot of control about leaving their houses due to staffing or transportation



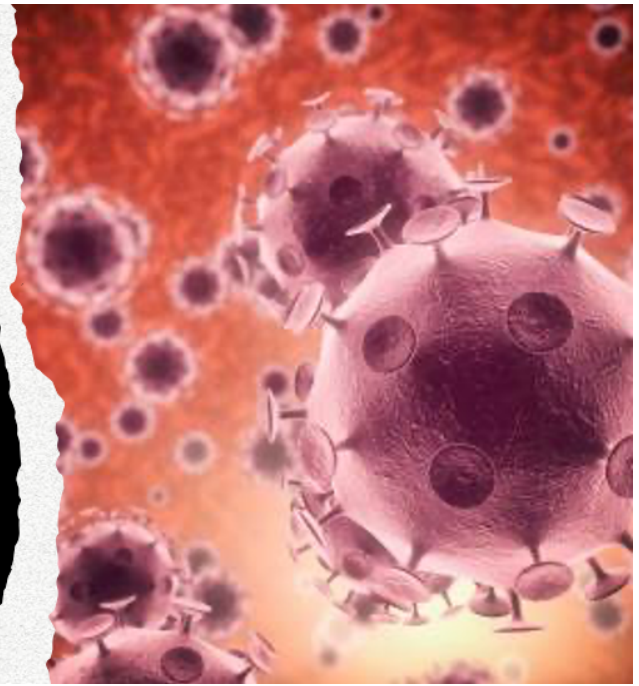


## Information about COVID-19

- People got some information from their group homes about things like masks and social distancing
- But people didn't seem to get complete information about the special risks that people living in group homes face



1. What have you experienced during the COVID-19 pandemic that you would like other people to know about? - Anna



2. What things do you think were done well for you and other people who live in group homes during the COVID-19 pandemic? - Sam



3. What things do you think could have been done better for people living in group homes? - Fran



4. What things still need to improve for people living in group homes? - Tony



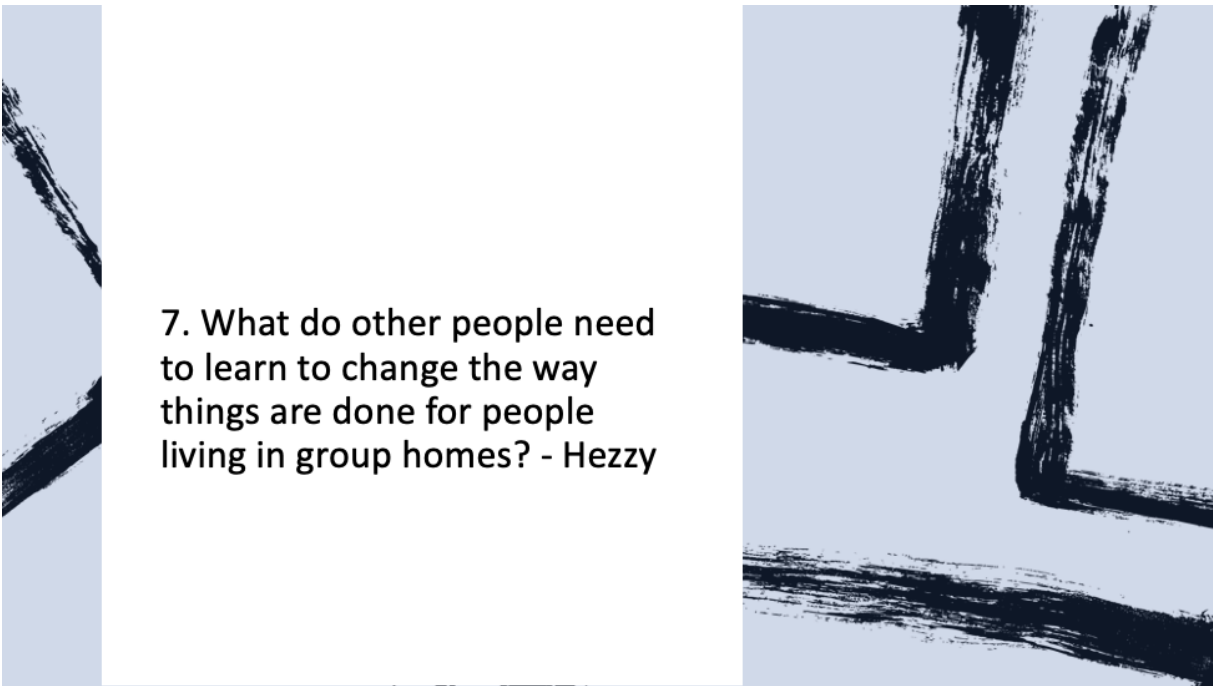




5. What have you learned during the COVID-19 pandemic about what group homes do and don't do? - Diana



6. What have you learned during the COVID-19 pandemic about what other people think about persons with intellectual disabilities? - Anne



7. What do other people need to learn to change the way things are done for people living in group homes? - Hezzy

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- Focus Group Discussion with Interviewees #1-6, August 15, 2022.
- Follow-up Interview with Group Home Resident #1, August 8, 2022.
- Follow-up Interview with Group Home Resident #3, August 19, 2022.
- Follow-up Interview with Group Home Resident #4, August 10, 2022.
- Interview with Group Home Resident #1, December 7, 2021.
- Interview with Group Home Resident #2, March 1, 2022.
- Interview with Group Home Resident #3, July 8, 2022.
- Interview with Group Home Resident #4, July 25, 2022.
- Interview with Group Home Resident #5, August 5, 2022.

- Interview with Group Home Resident #6, August 8, 2022.
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