UNITED STATES DISTRICT COURT EASTERN DISTRICT OF NEW YORK

| THE UNITED STATES OF AMERICA, |) |
|--|---|
| Plaintiff, v. |))) |
| STATE OF NEW YORK, |) Civ. Action No. 13-CIV-4165 (NGG) |
| Defendant. |)) _) |
| RAYMOND O'TOOLE, ILONA SPIEGEL, and STEVEN FARRELL, individually and on behalf of all others similarly situated, | |
| Plaintiffs, v. |)) |
| ANDREW M. CUOMO, in his official capacity as Governor of the State of New York, NIRAV R. SHAH, in his official capacity as Commissioner of the New York State Department of Health, KRISTIN M. WOODLOCK, in her official capacity as Acting Commissioner of the New York State Office of Mental Health, THE NEW YORK STATE DEPARTMENT OF HEALTH, and THE NEW YORK STATE OFFICE OF MENTAL HEALTH, |) Civ. Action No. 13-CIV-4166 (NGG)))))))))) |
| Defendants. |))) |

IMPACT OF COVID-19 ON CLASS MEMBERS SUBMITTED BY CLARENCE J. SUNDRAM INDEPENDENT REVIEWER*

^{*} The members of the Independent Review team Mindy Becker, Thomas Harmon, Stephen Hirschhorn, and Kathleen O'Hara contributed to the preparation of this report.

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I. Introduction

Early this year, the world turned upside down as a growing realization dawned that we were in the grip of a global pandemic caused by the 2019 Novel Coronavirus (COVID-19). As scientists and public health officials raced to understand the nature of the virus and the methods of transmission and infection, early recommendations focused on maintaining social distance, frequent handwashing and, with some inconsistency, wearing masks. As scientific consensus on these recommendations solidified, it soon became clear that people in congregate care facilities were at a heightened risk of infection because of the difficulty of maintaining social distance when confined in close quarters. Most facilities were ill-prepared to fully implement the emerging recommendations. Initially, there were widespread shortages of personal protective equipment (PPE) and hand sanitizer, and severe competition among governments, institutions, businesses, and individuals to procure these supplies, exacerbating the difficulty in obtaining them. Many businesses and offices instructed their staff to stay home and work from remote locations.

On March 13, 2020, the New York State Department of Health (DOH) issued a Health Advisory to all adult care facilities recognizing the especially high risk of severe morbidity and mortality at these facilities.¹ This Health Advisory immediately suspended all visitation to such facilities except when medically necessary. Direct care workers in congregate care facilities were recognized as "essential" and required to continue reporting to their jobsites despite the shortage of PPE and essential supplies needed to comply with the guidance issued by the DOH. Initial infection control surveys conducted by DOH in late April and early May 2020 resulted in Statements of Deficiencies citing violations of infection control standards at 12 of the 22 Impacted Adult Homes. Not surprisingly, it soon became apparent that many residents and staff in these facilities became infected with COVID-19.

According to data provided by the New York DOH, testing for COVID-19 during the month of June 2020 at the 18 of the 22 adult homes covered by the Settlement Agreement resulted in 103 positive results among the 1,586 consenting residents tested (representing 59% of the total census of these 18 homes). This equals a 6.49% positive rate for the residents tested. To put this number in perspective, for June 15 which is approximately the time when most of the adult home testing for June was done, the rate of positive results for the larger NYC region was one percent.² In the same month, the cumulative number of staff at these adult homes that were reported to have tested positive was 126. A similar calculation would likely yield a similar elevated rate of infection.

¹ New York State Department of Health, HEALTH ADVISORY: COVID-19 CASES IN NURSING HOMES AND ADULT CARE FACILITIES, March 13, 2020. (DOH Health Advisory)

² For the two week period ending June 15, 28,157 persons were tested, and 1.2% were found positive, and the 7-day rolling average was one percent.

In compliance with the Health Advisory, staff of the settlement providers (housing contractors, care management agencies [CMA], Managed Long Term Care Programs [MLTCP] and peer bridgers) and other agencies providing treatment and support services to class members ceased regular visits to the adult homes. Most closed their offices and required their staff to work from remote locations to avoid congregating in close quarters. Much of the work performed by these settlement providers to implement the Settlement Agreement and Supplemental Agreement,³ especially tasks that required face-to-face contact, slowed down significantly, or came to a halt. This included in-reach to class members to advise them of their options to access supported housing or other community alternatives; assessments to evaluate their qualification for services and specific needs for community support; interviews with housing contractors to determine their needs and desires for community housing; visits to view apartments or other housing in the community; and actual moves to such housing of their choice. Adult home residents were also discouraged from going in and out of the facilities to reduce their risk of exposure to the coronavirus and the related risk to other residents and staff. To a lesser extent, the effect of these changes in working conditions for the staff of settlement providers also affected class members who had transitioned to the community and were living in supported apartments or other community housing.

As these restrictions on visitation and movement in and out of these facilities took hold and became the "new normal," the Independent Reviewer contacted a sample of class members remaining in the adult homes, and those who had transitioned to the community, to check on how they were doing and how they were being supported by settlement providers during this extraordinary time.

II. Methodology

The Independent Review team developed a survey instrument to collect responses from a sample of class members and members of their support teams from settlement providers. The survey focused on the experiences of 40 sample class members during the period post March 13, 2020 when adult homes were closed to visitation due to the COVID-19 pandemic. The sample included 24 class members who expressed interest in transitioning but remain in each of the 22 adult homes; and 16 who had transitioned. The class members were served by each of the seven housing contractors and 36 were enrolled in seven Health Homes and served by 16 CMAs. Twenty-eight of them received Adult Home Plus Care Management (AH+CM) services and nine were on regular care coordination. Two were enrolled in the Program of All-Inclusive Care for the Elderly

³ Supplement to the Second Amended Stipulation and Order of Settlement ("Supplemental Agreement") (Doc. 196-1, filed March 12, 2018 in 1:13-cv-04166-NG-ST).

⁴ AH+CM provides a maximum caseload of 1:12, and has a requirement of at least four monthly contacts with class members on the caseload. In our sample, actual caseload ranged from 1:8 to 1:12. Regular care coordinators for our sample had caseloads of up to 60, but not all were class members. Prior to the pandemic, the expectation was one faceto-face contact per month, but it is now a phone contact every two weeks. The two PACE care coordinators serving

(PACE), one received non-Medicaid voucher services and one was no longer receiving care management services. Eleven of the 16 transitioned class members were receiving services from five MLTCPs.

In conducting the survey, Independent Reviewer staff conducted over 150 telephone interviews with the sample class members and their support team members mostly during the period from June 8 to July 21, 2020.

| | | | | Median Age | Median LOS (Range of Time) in |
|---------------------------|----|------|--------|--------------------|--------------------------------|
| | | Male | Female | (Range) | Adult Home or SH |
| Total | 40 | 24 | 16 | 64.1 (43.0 - 82.0) | |
| HRA Approved, | | | | | |
| not | | | | | |
| Transitioned ⁵ | 24 | 13 | 11 | 64.5 (43.0 - 78.7) | 5.3 years (1.3 - 24.2 years) |
| Transitioned to | | | | | |
| Supported | | | | | |
| Housing | 16 | 11 | 5 | 63.2 (46.9 - 82.0) | 1.9 years (4 months - 4 years) |

Table 1. Profile of the sample class members

All 40 of the sample clients were interviewed. Thirty-nine of the 40 class members were receiving care coordination services provided by AH+CM (28), the PACE (2) or regular care coordination services (9). One was no longer receiving this service. Care coordinators for 37 sample clients were interviewed, but two were non-responsive. Similarly, housing contractor staff (in-reach workers, case managers and their supervisors) for all 40 individuals were interviewed. Peers supporting 17 sampled individuals were interviewed (16 in adult homes and one in the community). In 12 cases, Nurse Care Managers (NCM) and Home Health Aides (HHA), and sometimes both, were interviewed. This was done for 11 of the 16 sample individuals who had transitioned and were receiving MLTCP services. But it was also done with the one non-transitioned member who was initially unavailable for interview as she was in rehabilitation.

The interviews focused on the class members' perspectives of how well they felt they were doing during the pandemic, and how well they were being supported by members of their settlement providers, including how frequently they were in contact with team members. Sample clients were also asked about their access to and use of PPE and social distancing practices, whether they received their stimulus check and, had they transitioned, conditions in their apartments.

Settlement providers team members were asked parallel questions about the class members' well-being, and frequency of contact. Additionally, they were queried about the

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persons in our sample had between 36 and 40 clients on their caseloads but each only served one class member and were expected to maintain weekly contact with them.

⁵ One person in the sample was a post class cap member.

difficulties of supporting class members during the pandemic and visitation restrictions. For AH+CMs, besides inquiring about the specific sample client, we asked about their caseloads generally and difficulties those individuals may be experiencing or that the AH+CM is having in supporting them.

III. Findings

A. Adult home residents

1. How are they doing?

In responding to the general question of how class members were doing, there was high consistency among the responses of class members, housing contractors and care coordinators, with the vast majority (75%) reporting that class members were doing well or had no problems. We received responses from all 24 adult home residents in the sample and the housing contractors and care coordinators supporting them.

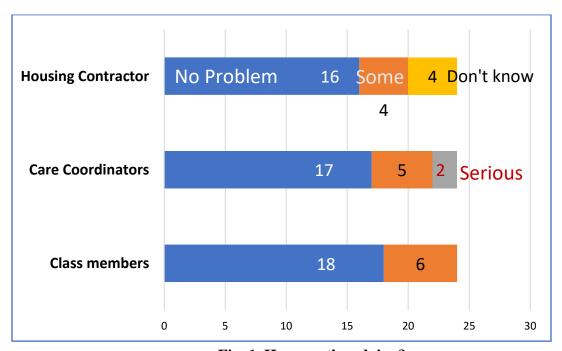


Fig. 1. How are they doing?

While it is encouraging to learn from class members and members of their support teams that few had experienced any problems, this finding must be considered with caution. Like members of the Independent Reviewer team, members of the class members' support teams received their information primarily from telephone contacts with the class members in the sample. Sometimes, it came from secondhand reports from adult home staff or other members of the support team. Several noted their inability to verify verbal telephone responses of class members and lamented the lack of face-to-face communication and the ability to observe body language and other physical communication cues. (discussed in more detail at pp.19-21 below)

But 25% of these class members indicated they were having some problem. Their reports were largely echoed by care coordinators, who had more contact with them than housing contractor staff – some of whom could not comment on how the member was doing as they had not had recent contact. The care coordinators, though, identified two class members who seemed to have serious problems.

- By both her own account and those of her service providers, Beatrice H. struggled with the significant isolation pandemic restrictions imposed. She also struggled to eat enough, finding her adult home's food even more unappetizing than before the pandemic. She was hospitalized on a psychiatric in-patient unit in June 2020, then spent almost a month in a rehabilitation facility. When interviewed in August 2020, she continued to find the pandemic restrictions difficult, and she was unsteady enough following her hospitalization that she changed her mind about transitioning, believing she would have too many problems in the community. Her providers continue to speak with her about her the option to transition, and her AH+ CM is pursuing neurological testing for her.
- The second was Lucinda S. who had been hospitalized for back pain, and then spent three months in a rehabilitation facility. She reported to Independent Reviewer staff the pain continues. Her care coordinator voiced this and also said it seemed that upon return to the adult home, she was engaging in increased alcohol abuse.

Other class members reported less serious concerns:

- Amos F. reported that he had tested positive for COVID-19 the week before our interview but had no signs/symptoms of the illness and was feeling fine. This was confirmed by his care coordinator.
- Laila R. has not been in the adult home since the pandemic because her father was hospitalized for surgery related to his cellulitis of the legs and a blockage in his heart. She has been living at home to help out and has been upset about her father's condition. In addition, her sister-in-law died from the virus.
- Jessica G. reported feeling anxious and bored, and having a hard time emotionally. "Everything is hard, we're stuck in our rooms, we have to eat off our beds, there's no room for a table. I can't go out, I find it impossible to go shopping."
- Both Carlos H. and his service providers noted pandemic restrictions keeping him confined to his room were extremely difficult for him. His pre-pandemic days revolved around his day program, where he "blossomed into another individual" and had a fulfilling social life. Without this key support, his emotional and cognitive state is unsteady. Carlos is also profoundly uncomfortable sharing a bedroom with another man under any circumstances and being with his male roommate for most of the day, every day, leaves him agitated, especially when his roommate invites male friends into the room.

2. Frequency and Helpfulness of contacts with providers

a. Care coordinators

| | Class members' Reports | | Care coordinators' Reports | |
|--------------------|------------------------------|------|----------------------------|------|
| Responses | 24 | 100% | 24 | 100% |
| More than weekly | 2 | 8% | 4 | 17% |
| Weekly | 17 | 71% | 17 | 71% |
| Couple times/month | 3 | 13% | 1 | 4% |
| Monthly | 0 | 0% | 2 | 8% |
| None | 2 | 8% | 0 | 0% |

Table 2. Frequency of Care Coordinator Contacts

As stated in the Table 2 above, 79% of non-transitioned members reported weekly if not more frequent contact with their care managers. Another 13% reported contacts of at least twice a month. Care coordinator reports were largely consistent. They reported weekly or better contact in 88% of their cases and at least a couple times a month contact in 4% of the cases. All class members reported finding these contacts helpful or very helpful. Of the 22 who responded to this question, only one said he wished the care coordinator could be of more help: help me move out! He said the same thing of his housing contractor.

| Class members' Reports ⁶ | | |
|-------------------------------------|----|------|
| Responses | 22 | 100% |
| Not Helpful | 0 | 0% |
| Helpful | 10 | 45% |
| Very Helpful | 12 | 55% |

Table 3. Helpfulness of care coordinator

b. Housing Contractors

Housing Contractor staff had less frequent contact with class members than care coordinators. In part, this reflects larger caseloads and in part the different role they play in implementing the Settlement Agreement. Their core function of performing in-reach, assessments which usually require face-to-face interviews, housing interviews and arranging visits to prospective apartments were all hurt by the restrictions on visitation at the adult homes.

As indicated in the Table 4, the majority of non-transitioned members (86%) reported monthly or less frequent contact with housing contractor staff; nine percent reported no contact during the pandemic. Housing Contractor staff reports were consistent with this with 88% reporting monthly or less frequent contacts with members.

⁶ Two class members were not included in this analysis. One declined to answer the question. Another has an AH+CM assigned to her but has not consented to AH+CM services.

| | | nembers' | HC | |
|--------------------|--------|----------|---------|------|
| | Report | S | Reports | |
| Respondents | 22 | 100% | 24 | 100% |
| More than weekly | 0 | 0% | 0 | 0% |
| Weekly | 2 | 9% | 2 | 8% |
| Couple times/month | 1 | 5% | 2 | 8% |
| Monthly | 9 | 41% | 12 | 50% |
| Less than monthly | 8 | 36% | 8 | 33% |
| None | 2 | 9% | 0 | 0% |

Table 4. Frequency of housing contractor contacts

Housing Contractor staff received grades lower than care coordinators for their helpfulness, with 36% of the class members reporting them to be Not Helpful. It is likely this results from their less frequent contact and the adverse effect that limitations on visitation in the adult homes has had on their ability to assist class members with finding and moving into community housing.

| Class members' reports | | | | |
|------------------------|----|------|--|--|
| Respondents | 22 | 100% | | |
| Not Helpful | 8 | 36% | | |
| Helpful | 8 | 36% | | |
| Very Helpful | 6 | 27% | | |

Table 5. Helpfulness of housing contractor staff

A few examples of class members' reports:

- Emmett W. wants a one-bedroom apartment and does not want to share his housing. He thinks the housing contractor could be more helpful by showing him apartments.
- Jorge R. says he wants a one-bedroom but has had no contact, no leads in months from the housing contractor. He says the housing contractor could be more helpful by showing apartments once crisis is over. The housing contractor case manager reports only one contact in last three months, but says they made numerous attempts.
- Amos F. wants to move, was shown an apartment he liked, but he did not file a 30-day notice before the pandemic hit. He reports he has not heard from the housing contractor in months, which is confirmed by the housing contractor.
- John W. wants to move but has not heard from the housing contractor in months. The housing contractor claims contact about a "month or so ago" but most contact was pre-COVID-19. He said the housing contractor could help by showing him apartments, helping him move; he says he has been waiting for nine months since approval.

Four other class members (Cassidy G, Geoffrey V, Laila R. & Michael G.) said they have not heard from housing in months. Although they do not want to move right now or want any help from the housing contractor at present, they complain that the housing contractor has been of no help.

3. Peer support

The Supplemental Agreement requires the assignment of at least three full time peer bridgers to each of the Impacted Adult Homes to assist class members in all phases of the transition process. The sample included 12 class members served by each of the two peer bridger agencies, Community Access and Baltic Street. Like other settlement providers, peer bridger agencies have also been affected by the restriction on visitation to adult homes and have been left to rely upon telephone communication with class members. Settlement provider staff have reported difficulties in contacting residents of adult homes via telephone, especially if they are relying upon the adult home phone system. Three adult homes do not provide phones in resident's rooms, leaving them to rely upon communal phones in the lobby or hallway. Also, callers must sometimes navigate the adult home switchboard to reach residents, which is not always successful.

The two peer bridger agencies obtained 750 cell phones for distribution to class members and post-class cap residents in adult homes. Through this distribution and other sources, 71% of the class members in our sample had cell phones, although a few reported that they did not know how to use it or keep it charged.

We spoke with 20 of the 24 class members in the sample about the frequency of their contacts with peers, with four declining to respond. Half of those in adult homes who responded reported weekly or some recent, but unspecified contact, with peer agencies. All reported that the peers they have been in contact with have been helpful. Another 50% reported less than monthly or no contact since the pandemic began or could not recall contacts or recognize the names of peers assigned to their homes.

Peers from agencies serving 17 of the sample members were interviewed. In six (35%) of the cases, they indicated that the pandemic has not posed challenges in supporting individuals. Usually (65%), they reported it did. Most difficulties cited pertained to maintaining contact with class members over the phone and difficulties in trying to establish relationships with persons they had never met before and to maintain relationships with class members they had met before the pandemic but had not seen since and who forgot them without face-to-face contact.

During the pandemic, the peer agencies experienced staffing shortages and realigned peer bridgers among homes which resulted in some peers "cold calling" members to introduce themselves and attempt to establish a relationship. Examples of some peer comments on difficulties encountered are below. Also, notable that among the 16 transitioned members in our sample, one transitioned in December 2019 and still maintains contact with her peer which she finds helpful.

- Emmett W. is hard to reach and he never remembers who you are when you call him or why you are calling (AH+CM said the same thing). Peer reports he spoke with Emmett on 6/30/20. Emmett had no recollection of speaking with any peer during the crisis.
- Delia P.'s peer reports that sometimes it is difficult getting ahold of people over the phone when he has to go through the adult home. He said he knows cell phones are being distributed and he is waiting to get the phone numbers for the people who get them.
- Richard Mc.'s peer noted that speaking over the phone with people has opened up doors. People who would not talk to you face-to-face will do so now over the phone. This is good. But the virus is a two-edged sword; it has cut off visits and the ability to see "a familiar face" and have a one-on-one conversation.
- Gigi T.'s peer reports that since we cannot visit people, we have to maintain weekly contact. Using the telephone for people I don't know is difficult. It is hard to establish a rapport with someone you have never met in person, looked in the eye and talked to. For people we have worked with face-to-face pre-COVID, the bonds are strong. But for others, when we call, we're like strangers..." Who are you, I don't know you."
- Cathy V. is served by Community Access and has had a different peer assigned. The peer said that due to staffing shortages and the inability to visit people, we are cold calling members. It is hard to establish a relationship.

2. PPE and social distancing

Aside from the restriction on visitation, the DOH Health Advisory directed facilities to require staff and residents to wear facemasks while within six feet of other persons, cancel group activities and communal dining, encourage residents to remain at home in areas of high concentration of positive coronavirus cases. The Health Advisory also referenced guidance from the federal Centers for Medicare and Medicaid Services⁷ which further addressed the use of PPE such as facemasks, social distancing, hand hygiene and screening of visitors.

Twenty-three of the 24 adult home residents in our sample responded to questions about the availability of PPE and social distancing practices. Ninety-six percent (22/23) reported no problem with the availability of masks, and 78% (18/23) said there was no problem with social distancing.

These responses contrast with the findings of two series of infection control surveys conducted by the DOH at the Impacted Adult Homes between late April and early June 2020 which resulted in 12 Statements of Deficiencies being issued to Impacted Adult Homes. In several of

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⁷ https://www.cms.gov/files/document/qso-20-14-nh-revised.pdf.

these homes, surveyors found an absence of six-foot distance markings in areas where people congregated; lack of hand sanitizer; residents observed in the hallways without masks, walking by staff who did not encourage them to wear masks; residents and staff wearing masks inappropriately; overcrowded elevators; residents congregating outside the home and smoking without proper distancing.

The different results cannot be explained solely by the different dates of the DOH surveys and the Independent Reviewer team's interviews which generally occurred later. More likely class members were responding about their own behavior rather than the more general conditions in the adult home and that, if they did not see a problem, it may reflect their perception these are not serious issues.

- One class member, Ricardo E., responded there was no problem with PPE but then admitted it was very difficult to get replacements for the disposable masks his adult home supplied. He texted the reviewer a photograph of his room showing a friend sitting less than six feet away from him, with his facemask pulled down to his chin.
- Class members have also reported on the lack of replacement masks at some facilities.
- Another class member, Regina G., is in an adult home that has provided masks and gloves and discussed safety protocols like distancing. While she reports observing these protocols, she also says that she enjoys going outside to walk, going to stores, and has gone to at least one restaurant with her boyfriend. She also spends time in her boyfriend's room and did not seem to consider the potential consequences of being in close contact with him, his roommate, and then her own roommate.
- Class member Gigi T. reported no problem and that she knows about social distancing and keeps her distance. When asked about using the elevator, she said she tries to take it by herself, but if someone else gets on she gets off suggesting that others in the home may not be respecting social distancing requirements.
- Ricardo E. expressed frustration that other residents were not following the rules and it was impossible to maintain social distancing at his home.

B. Transitioned class members.

1. How are they doing?

There was more variation in the responses of transitioned class members, care coordinators and housing contractors to this question than with adult home residents. We received responses from all 16 class members in the sample and from their housing contractors, and from care coordinators for 13 of the 16 in the sample. One person opted out of care coordination. We could not reach two other regular care coordinators despite multiple attempts.

As stated in figure 2 below, most of the 16 transitioned class members (81%) reported that they are doing well or had not had problems during this period. There was less agreement with this assessment by care coordinators and housing contractors than for the adult home residents, with 54% and 63% respectively finding no problems. Where problems were cited, they usually pertained to long-standing, non-COVID-related health problems (diabetes, COPD, CHF, ongoing substance abuse, etc.) or maintenance issues with the apartment. Based on responses to this question, service providers, who are more inclined to identify a problem than the class member experiencing it, were often on top of the issue and addressing it.

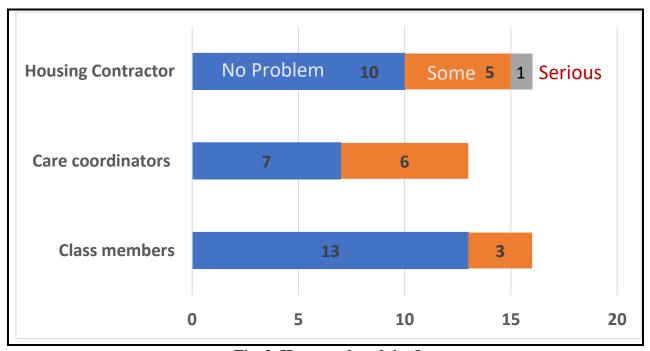


Fig. 2. How are they doing?

- Amanda L. transitioned on March 4, 2020, shortly before the DOH restrictions on visitation went into effect. Her AH+CM, housing contractor and MLTC have managed well in providing her support in managing her diabetes and her right-sided hemiplegia. Her housing case manager still visits her twice a month which provides an on-site presence and allows her to address the issues that arise. The MLTC NCM has worked to get approval for a new battery for her wheelchair and has installed a new HHA after there were issues with her service. Her providers also work well as a team in supporting her. With an involved family and a caring team of providers, Alicia has been well managed and supported since her transition from the adult home.
- Providers serving Sylvia J. have managed well during the pandemic. Their work is anchored by Sylvia's sister who provides HHA services, helps her budget her money, and encourages her participation in volunteering at a church twice a week to help feed others during the pandemic, while socially distancing. The relationship with the peer specialist

from housing, which has been a constant in her life through the pandemic, is the most consistent means of support, outside of her family. While it has been labor intensive to assign a part-time peer to her for two half days a week, since 2016, this has been invaluable during the pandemic.

- Guillermo R. transitioned on March 24, 2020 shortly after the DOH restrictions on visitation. He was then hospitalized for a week in June for breathing issues unrelated to COVID-19 and is very fearful of getting the virus. The nurse from the housing contractor visited him during the pandemic right after the move, spoke with him twice a week for the first month and then once a week until he was hospitalized. She then spoke with him twice after the hospitalization and encouraged him to move around in the apartment and use the long hallway he has in his studio apartment to avoid another clot due to immobility. She encouraged the HHA to clean up all boxes and other fall risks in the apartment and kept the case manager informed. She also encouraged Guillermo to use his rollator and on nice days go outside while maintaining social distance. She also spoke with VNS when they started and discussed glucose checking three times a day with him and followed up with VNS after a week.
- When first interviewed, Sam K. reported he and his providers were handling the pandemic well; his providers were all in consistent, frequent contact with him and he was following their guidance. However, Sam then revealed a litany of serious problems for which he had been asking for help since before the pandemic. He was frustrated that his providers offered so much contact around the pandemic itself, yet when he asked for help with longer standing problems, he received little support. Several of Sam's problems arose following the September 2019 amputation of his leg and a rocky recovery including: ongoing, severe pain; insufficient or missing services to support his recovery, such as fewer HHA hours than he desired and no physical or occupational therapy; the suspension and only partial reinstatement of his Social Security benefits. Because these problems were not addressed before the pandemic, they worsened once pandemic restrictions limited what service providers could do. For example, Sam's prosthetic was delayed until June 2020, meaning he spent six months navigating an apartment and building that was not fully accessible; his providers could do little to help once pandemic restrictions were in place. Yet when his prosthetic arrived and eased restrictions allowed for the possibility of physical therapy, none of his providers helped him connect to this service. Without physical therapy and related services he found wearing his prosthetic increased his already severe pain, and he questioned what good it did for service providers to call him" all the time" if the calls did not lead to needed services and support.

2. Frequency and Helpfulness of contact with providers

a. Care coordinators

As indicated in Table 6 below, all transitioned members interviewed reported at least monthly contact with their care managers, with 54% reporting weekly or more frequent contact and an additional 15% reporting contact several times a month. (It should be noted that half of the transitioned members have been stepped down from AH+CM to less intensive care coordination). All members enrolled in AH+CM reported weekly if not more frequent contact with their care coordinators. Those enrolled in regular care coordination reported at least monthly contact with their care coordinators and many more often. Twelve of the 13 care coordinators interviewed reported no in-person contact with the members since the COVID outbreak. Most indicated that they would visit if there was an urgent need. All class members reported that their care managers have been helpful.

| | Class members' Reports | | Care coordinators' Reports | |
|-------------|---------------------------|------|-------------------------------|------|
| Respondents | 13 | 100% | 13 | 100% |
| More than | | | | |
| weekly | 4 | 31% | 5 | 38% |
| Weekly | 3 | 23% | 3 | 23% |
| Couple | | | | |
| times/month | 2 | 15% | 3 | 23% |
| Monthly | 4 | 31% | 2 | 15% |

Table 6. Frequency of contact with care coordinators

Some problems reported are:

- Amanda L.'s AH+CM reports she does not seem to understand the seriousness of her diet to manage her diabetes and was hospitalized for high blood sugar in May 2020.
- Guillermo R.'s AH+CM reports that because of his health concerns (COPD, Diabetes, and clots he developed in the hospital) Guillermo feels vulnerable and tries to be extra cautious. Sometimes he can get overwhelmed, which is exacerbated by his watching the news too much.
- The regular care coordinator for Bosco H identified problems in his follow-up with his medical concerns, including COPD, asthma, and SOB, which she tries to assist him with. Because of his comorbidities he feels vulnerable and fears leaving the house.
- Sam K., who had done well in the community until his September 2019 leg amputation, had been stepped down to regular care coordination. Although his care coordinator seemed to do everything in her job capacity to address his problems, she reported a caseload at

between 60 to 90 individuals, which spread her efforts thinly, particularly once several individuals contracted COVID-19. Sam's care coordinator continued to make at least one call per month to him during the pandemic, but the contact was not enough to know or respond to his many needs. Following this review, Sam was recognized as needing a higher level of care and in August 2020 agreed to enroll in Pathway Home.

c. Housing Contractors

Of the 14 class members who responded to this question, 86% reported weekly or more frequent contact with housing contractor staff by telephone or other means which is consistent with the housing contractor reports that 82% of staff had a similar frequency of contact. The remainder reported speaking with staff twice a month. In terms of face-to-face contacts, 11 of the 16 housing contractors interviewed reported visiting the class members at least monthly. Three reported visiting less than monthly and two reported no visits since COVID. The reported visits sometimes occurred in conjunction with delivering personal allowance checks, and usually occurred in spaces where appropriate social distancing practices could be observed.

| | Class members' Reports of contacts | | HC Reports of contacts | |
|--------------------|------------------------------------|------|------------------------|------|
| Respondents | 14 | 100% | 16 | 100% |
| More than weekly | 6 | 43% | 7 | 44% |
| Weekly | 6 | 43% | 5 | 38% |
| Couple times/month | 2 | 14% | 4 | 31% |
| Monthly | | | | |
| Less than monthly | | | | |

 Table 7. Frequency of contact with housing contractors

All but one of the class members who responded reported that the housing contractor staff were helpful or very helpful. The one that did not was experiencing maintenance problems in the apartment and complained that the staff member was not polite.

- Amanda L.'s housing case manager reported that she had struggled managing her diabetes that resulted in a hospital stay in May and has had problems getting insurance approval to replace the battery on her motorized wheelchair. In addition, she had recently run out of money for food due to the amount she spends on cigarettes, with which her case manager assisted.
- Sam K. had long-standing problems with his housemate who badgered Sam and his HHA for money; stole and used his debit card; engaged in threatening behavior; and invited friends to the apartment, one of whom stole his phone. These conflicts were exacerbated once the restrictions imposed in the wake of the pandemic forced them to spend more time together. Although his housing case manager made regular phone check-ins, these concerns he expressed during the calls went unaddressed. Following this review, his

housing contractor initiated plans to move his housemate to another unit and initiated a transfer to a Brooklyn housing contractor so Sam could achieve his long term goal of living near his daughter in a disability-accessible apartment.

d. MLTCP

Eleven of the 16 transitioned members were receiving services through five MLTCPs which included HHA services from two to seven days a week for several hours a day and periodic visits by nurses and NCM. All members but one said the pandemic did not interfere with services. The one who reported a problem indicated his HHA had been exposed to the virus by another client and so both he and his HHA self-quarantined for 14 days, during which his agency sent two substitute HHA to assist him. Most members were also satisfied with the help they received from their MLTCP staff, though one reported he has a "bad feeling" about his newly assigned NCM who would not give him her cell phone number and another expressed frustration with the lack of support through a confusing appeal process during which he was twice denied increased HHA hours despite what he believed to be strong need. The HHAs and nurses with whom we spoke reported that the pandemic has not affected their work or ability to maintain contact with members. Notably, the HHAs are the only staff of settlement providers who have maintained frequent, consistent, personal contact with class members since the COVID-19 pandemic.

- Bosco H. benefits from a positive relationship with his HHA, Amy, who has served him since his transition from the adult home over a year ago. Of particular note, during the pandemic, Amy has continued to travel on public transportation, over two hours each way by land and sea, from her home in Brooklyn to Bosco's in Staten Island, to work with him three days a week, without interruption.
- Belinda G., in her 80s, has fared well during the pandemic. However, underlying medical conditions led to severe edema in her legs in May 2020. The only service provider who could see this problem in person was her HHA, who called an ambulance once she believed the problem severe enough to need immediate treatment. Belinda's HHA not only connected her to treatment but helped ensure her other service providers were fully aware of her problem, allowing them to be more attentive to her medical needs. During the pandemic Belinda's HHA has also taken on other coordination tasks, including speaking to the building super and housing contractor about maintenance concerns (e.g., malfunctioning stove, low water pressure). Finally, the HHA has taken on more grocery shopping and food preparation duties for both Belinda and her roommate, carefully monitoring how much SNAP money Belinda has so she will have sufficient food through the end of each month.
- Bill B. reports a great relationship with his HHA, who had never missed a day of work during the pandemic until learning one of his other clients had been diagnosed with

COVID-19. Both Bill and his HHA went into 14 days of self-quarantine, during which the CHHA sent two substitute HHAs to help him. Bill notes all the HHAs have gone above standard services during the pandemic; for example, one of the substitute HHAs brought him special foods and another, concerned his cleaning supplies were insufficient, brought her own, stronger cleaners to ensure his apartment would be germ-free.

3. Living conditions

Class members were asked were they experiencing any problems with their living conditions (maintenance, problems with housemates, food, and financial sufficiency). Only one did not respond. Sixty percent of respondents (9) reported no difficulties. Six or 40% reported some difficulties. The most frequently cited problem was a maintenance issue followed by financial and food insecurity. And one cited housemate issues. Some of the six members cited a combination of issues. Five of these members reported that settlement providers were helping with these issues, although one (Sam K.) wished housing would do more in terms of his problematic relationship with his housemates and his desire to transfer to a disability-accessible unit in a different borough.

- Amanda L. experienced problems with mice infestation that are being addressed by the housing contractor and the building superintendent.
- Bosco H. had problems with his doorbell, his outdoor light and mice infestation that were addressed or being addressed by the housing contractor.
- Guillermo R. experienced problems with his A/C and his shower soon after he moved in during March, which were addressed promptly by the housing contractor.

C. General observations

1. Perspectives of care coordinators, housing contractors and peer bridgers on the difficulties of supporting class members during the COVID-19 crisis

During the survey, care coordinators, housing contractor staff and peer bridgers were asked how difficult it was to support members in our sample and others on their caseloads during the pandemic. As indicated in the tables below, the vast majority of care coordinators indicated experiencing some or serious difficulties in supporting members in our sample (68%) or others on their caseloads (97%). We received responses regarding 37/40 class members in the sample and regarding 34 other class members who were on the interviewed care coordinators' caseloads.

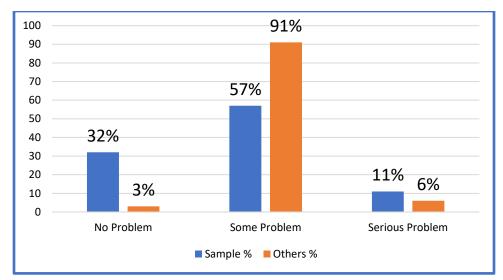


Fig. 3. Care coordinators reports on difficulties serving sample class members vs. others on their caseloads

Most peers (65%) reported about the same proportion of problems. Housing contractor staff, though, were evenly split on this issue with 50% reporting no problem and 50% citing some problems.

| | Peers | Housing Contractor |
|-----------------|-------|--------------------|
| Responses | 17 | 38 |
| No Problem | 6 | 19 |
| Some Problem | 10 | 19 |
| Serious Problem | 1 | 0 |

Table 8. Housing Contractor and Peer Bridger reports on difficulty serving sample class members

Examples cited by interviewees are presented below. Some of the common themes which ran through them included: the inability to meet people face-to-face to assess how well they were doing; problems associated with securing needed services/documents online as many government offices were closed; the inability to tour apartments to spark and capitalize on individuals' interest in moving; the difficulty in keeping that interest up solely by phone calls and no visits; the difficulty in contacting members via the adult home phone system; with class members new to care coordinator caseloads, the difficulty of "cold calling" the individual to introduce oneself and help the member understand transition related services and supports; relying on adult home staff for tasks normally undertaken by settlement providers (e.g., connection to outside service providers, often via telehealth during the pandemic) . The latter difficulty was compounded by adult home staff not always effectively following through on the tasks class members needed done.

• A care coordinator for Amanda L. cited not visiting as problematic "you have to go with what she is saying without being able to check on what food is actually

being bought and consumed, and there is no way to verify what medication she is taking- can't do pill count."

- For Lucinda S., the care coordinator spoke of the difficulty associated with relying on adult home staff to do things she would have done, such as scheduling and arranging for transportation to medical appointments. Before the pandemic, she would have done this herself and escorted the member to the appointments. Now the adult home is not scheduling timely transportation, appointments are being missed and some of her clients cannot manage telehealth appointments on their own.
- Emmett W. is eager to move and has been approved. But he needs things that cannot be provided at this time, such as a new birth certificate and medication training.
- The care coordinator for Emmett W. reported that many clients in the adult homes have forgotten who she is and that they had met her before. They used to know who she was when she visited every Wednesday, but now they do not when her only contact is by phone. You need to put a face to the name.
- Housing contractor staff for Delia P. said it is problematic that they cannot visit members in person or give them tours of apartments. The only contact is by phone, which is difficult to do.
- The care coordinator for Yolanda F. reported that she will move and has been approved but needs certain things before it can happen which cannot be arranged. She needs IDs, but her birth certificate has a different name on it so it has been difficult getting her a new one given office closures; she needs an intake with a psychiatrist and therapist near her new apartment which is difficult to arrange, and needs medication training. Her housing contractor staff person cited how difficult it is to keep class members like Yolanda and others interested and motivated to move when all you can do is call them, which itself is sometimes difficult.
- The AH+CM for Geoffrey V. reported that not being able to see clients face-to-face, to visit them, to see their apartments, to read body language when you ask how they're doing and they say "OK," is a problem. COVID-19 has also changed people's minds about moving. Two of her clients wanted to move, but now they are having second thoughts.... "what if I get sick, I have other medical conditions, etc." They feel safer in the adult home even though social distancing would be easier if you had your own apartment.
- In cases of more significant medical or psychiatric distress, settlement service providers reported only learning of issues after a crisis, and sometimes not gaining full details, as they could not visit class members or outside providers in person.

For example, Belinda G's service providers only realized the severity of the edema in her legs when her HHA, the one provider who regularly saw her in person, called for an ambulance so she could be treated immediately. Beatrice H's providers displayed differing understandings of what led to her June 2020 hospitalization, and despite conscientious efforts to speak to hospital and rehabilitation staff during her stay, they did not learn the specific diagnoses she may have received while in these facilities.

2. Stimulus checks

During interviews, we asked class members had they received their stimulus checks issued during the pandemic. Thirty-seven of the 40 sample clients responded to the question. (Two non-transitioned clients and one transitioned member declined to discuss the issue.) The vast majority, 78%, reported receiving the check. Others reported they did not or were unsure. Where class members were unsure or responded No, we ensured the care coordinators knew this and were following up. Individuals reported spending the money on food, a foot massager or other items they wanted. Some reported keeping it safe in the bank.

• Ricardo reported spending his money to clear debts and purchase new clothing. He also put some stimulus money in his bank account. Similarly, Jessica said she was thinking about using some stimulus money to purchase new toiletries and saving the rest. Bill also put his stimulus check into his savings account, describing how he hoped to use the money for a vacation with friends once the pandemic has passed.

At least one housing contractor (ICL) has offered class members in receipt of their stimulus check the option to pay down any rent arrears they may have. The amount class members pay is up to them, and they receive documentation from the housing contractor that they have paid down their debt.

| | All Class members | | Non- Transitioned | | Transitioned | |
|-------------|----------------------|------|----------------------|------|--------------|------|
| | # | % | # | % | # | % |
| Respondents | 37 | 100% | 22 | 100% | 15 | 100% |
| No Problem | 29 | 78% | 18 | 82% | 11 | 73% |
| Problem | 8 | 22% | 4 | 18% | 4 | 27% |

Table 9. Receipt of stimulus checks

IV. Conclusions

In a period of unprecedented difficulty, the staff of settlement providers has adapted well to meet the challenge of continuing to support class members in adult homes and the community. Despite severe restrictions on their ability to continue in-person meeting and visits to adult homes, they have nevertheless continued to make contact as best as they could, with many making more

frequent contacts than the minimum required. Most of the class members we contacted reported finding their contacts helpful, even as some expressed frustration with the restrictions and lack of movement on their desire to leave the adult home. Most reported that they are doing well. The efforts of peer bridger agencies to help facilitate communication by making available 750 cellphones and helping to distribute them is particularly notable. Similarly, commendable is the work of the MLTCP agencies and HHAs who continued to go into the apartments of class members to provide them the necessary services

While these findings are reassuring, one cannot lose sight of the reality that class members continue to live in congregate care facilities where they face a substantially elevated risk of infection with COVID-19 which is particularly dangerous to people who are older and in compromised health condition, as many class members are. Now that we are over five months into the period of restrictions, some of which are being slowly loosened, we are in a "new normal" and that a return to work in a pre-crisis environment is unlikely for several months, and perhaps longer. And the restrictions being eased can be re-imposed quickly should there be a new infection at the recently re-opened adult homes.⁸

This makes it essential and urgent to find effective ways to continue the work of helping class members, who so desire, to transition to supported housing or other community living options. A key requirement is assisting class members and settlement providers to communicate in a timely and effective way to facilitate transition related activities, as discussed in an earlier memo from the Independent Reviewer to the parties. The initial expectation that distributing cellphones to class members without them would help overcome the problems of relying on adult homes' phone systems is less effective than envisioned. Surveys by peer bridger agencies indicate a low level of usage of these cellphones and many class members reporting difficulties in using these devices, keeping them charged, answering calls, or losing them. As described in this report, accounts from settlement providers also show the limitation of communication that relies exclusively on telephone contact.

But perhaps more fundamentally, the experience over the past several months should prompt a re-thinking of the entire implementation process of the Settlement Agreement. For years we have been decrying the cumbersome, time-consuming process to move people out of adult homes and into supported housing or other alternatives. While there have been some process changes made, and others being considered, to date none of these has made much of a difference in speeding the transitions of class members out of adult homes. In fact, transitions have slowed down to a trickle.

Meanwhile, maintaining the infrastructure required by the processes created requires the

 $^{^8}$ See https://coronavirus.health.ny.gov/system/files/documents/2020/07/health-advisory adult-carefacilities-visitation final-v8.pdf

⁹ Implementation of the Settlement Agreement in the time of COVID-19, June 15, 2020.

commitment of substantial resources which seem to be benefitting a dwindling number of class members. This includes money provided to the housing contractors to rent apartments, hire staff (although they carry many vacancies), to pay assessors who perform a few assessments; and to pay two peer bridger agencies who also carry many vacancies, etc. In seven years, the current processes and infrastructure have moved less than 1,000 people. Most class members continue to live in adult homes and now with the heightened risk to their health and their lives.

We think it is time to consider experimenting with an alternative process that directly empowers class members to move out of the adult home if they so desire. In lieu of the current multi-step process, class members would be offered the option of a voucher equivalent to the prevailing cost of supported housing in the four boroughs of New York and funds for the help of a care coordinator/peer bridger/navigator (who could be the existing care coordinator, a family member or a friend) to help them find and secure an apartment of their choosing from any current housing contractors, other housing agencies or the housing market. They would continue to have the choice to retain the services of a Health Home and/or MLTCP to provide the Medicaid-funded support services they would need in the community. Perhaps class members would think differently about their choices with this type of control over their own decision-making, rather than the process that has been created. Would people who have said they are disinterested in moving give it a second thought with this type of control?

V. Recommendations

1. Perhaps the most important take away from the interviews with class members and settlement providers is the critical need for an effective and reliable system of communication available to class members, especially when in-person meetings are sharply restricted. Since the conditions that affect class members vary tremendously among them based not only on their own ability to navigate technology but also the conditions in the adult homes in which they live and the support available within them, the solution for each class member must be individualized and personalized. The best vehicle to address this need is the Person Centered Plan. Settlement providers must be directed to work with class members to incorporate into these plans changes necessitated due to the circumstances that exist in the wake of the pandemic. A key element of the changes to these plans is a communication strategy based upon the environment affecting each class member. For some class members who live in adult homes with effective and reliable telephone access to make and receive calls through the adult home phone system, there may be little or no need for changes. Sometimes, what may be required is an effective system for delivering messages to class members. There may be a need for a wider distribution of cell phones and training in appropriate usage of the devices. The State should set priorities for such a distribution, perhaps starting with the three adult homes which do not provide for in-room telephones. We recommend the development of a plan that addresses the needs of class members in each of the adult homes, that identifies each class member's needs, specifies who is responsible for providing a cellphone if one is needed and assisting the class member in using it effectively, and that monitors the timely implementation of the plan.

- 2. The same approach is required for increasing the use of technologies for videoconferencing and telehealth to facilitate effective communication when in-person meetings may be difficult or impossible.
- 3. As is evident from this report, some care coordinators have managed to navigate online systems to enroll their clients in SNAP, secure IDs, and perform other essential transition related tasks. Yet, most others report it is impossible to complete these tasks under the current conditions and that they must await the reopening of offices. We recommend using the skilled care coordinators to train their colleagues to use online resources effectively during a time when their preferred method of completing tasks is not available.
- 4. While the State's issuance of new guidelines for the resumption of visits by settlement providers to the adult homes is welcome, it is still a limited opportunity which relies heavily on off-premises meetings with class members. It is also a fragile opportunity that can be rescinded with the emergence of a single case of infection at an adult home which would shut down transition related work off premises for all class members, including assessments, housing interviews, and apartment tours. We recommend considering less drastic responses to the reemergence of infections, including isolation of infected persons in separate areas of the adult home, and using hotel rooms to provide isolation, both of which would limit the adverse effect upon the remaining residents of the adult home.
- 5. This review also revealed the extent to which long-standing problems that preceded the pandemic have gone unaddressed during this period of restrictions. There may be a temptation to view the pandemic as an all-purpose excuse for the lack of progress in addressing these issues —such as apartment maintenance, housemate conflicts, health care attention, etc. The State and its settlement providers must hold themselves accountable to continue to support the class members and attend to their well-being and safety despite the obstacles.