THE IMPACT OF COVID-19 ON CONSUMER DIRECTION IN NEW YORK STATE
# Table of Contents

Executive Summary .................................................. 3

Regions ................................................................. 4

Personal health assessment and safety concerns .............. 5

Concern regarding the impact of COVID-19 on workforce and availability of PAs 8

Fear of institutionalization in nursing homes due to loss of control 10

Effect of the pandemic on personal assistant recruitment and retention 12

A snapshot of current PA recruitment activities .............. 13

Access to medical supplies and personal protective equipment (PPE) 19

Discussion and Recommendations .......................... 24

Conclusion .......................................................... 26
Executive Summary

COVID-19 has been disruptive worldwide, but for people with disabilities and seniors who rely on long-term care, the impact has had devastating effects. Because of the highly contagious nature of COVID-19, state government officials have heeded the advice of medical professionals and issued “shelter in place” directives in order to slow the spread and reduce the strain on our healthcare system while researching potential treatments and vaccines. However, the disease has ravaged nursing homes, with those in these institutions accounting for over 40% of the fatalities from COVID-19. Meanwhile, community-based options provide demonstrably better services for people; however, this does not mean that those who use community-based options such as Medicaid’s Consumer Directed Personal Assistance (CDPA) program have not experienced problems.

In an effort to determine the impact of the COVID-19 crisis on Medicaid recipients using CDPA, the Consumer Directed Personal Assistance Association of New York State (CDPAANYS) surveyed consumers. The survey sought information about how the COVID-19 pandemic is affecting their services, including an assessment of their own risk of infection, the availability of PAs to staff their hours, their level of concern about institutionalization, and the level of difficulty acquiring PPE. The survey was open for responses for three weeks and we received responses from 174 CDPA consumers and designated representatives. Responses from those who did not identify as a consumer or designated representative were ignored. The survey was distributed via email, social media, and broader disability listservs.

Respondents were broken down by the following regions to identify areas that may be faring better or worse in these departments: Capital District (including the North Country), Central New York, Hudson Valley, Long Island & Westchester, New York City, and Western New York. While we promoted this survey to our members statewide, regional representation was a bit skewed. Western and Central New York, and to a lesser extent, the Capital District, were oversampled, while the Hudson Valley and Long Island & Westchester were undersampled. The survey slightly undersampled New York City and the Hudson Valley and Long Island/Westchester was dramatically undersampled. Western New York and Central New York were oversampled. Despite the sampling, results appear consistent and we are confident that the findings represent an adequate picture of the experience of those relying on CDPA.
In which region do you live?
Personal health assessment and safety concerns.

Respondents were asked to assess their risk of complications if they were to contract COVID-19, as well as their level of concern on a scale of 1 through 5 (1 being the least concern and 5 being the most) that they and their personal assistant(s) would contract COVID-19. The results clearly demonstrate that those who rely on CDPA recognize that they are at high risk of catching the disease and are concerned about contracting it.

More than two-thirds of participants from all regions feel that they are at high risk for complications or death if they were to contract COVID-19, including 88% of those living in Central New York.

An overwhelming majority of consumers recognize that they are at higher risk of contracting COVID-19.

Even in New York City and Long Island/Westchester, where affirmative responses were lowest, seven out of ten respondents indicated they felt that they were at greater risk of contracting the disease. In every other region, the number was over 80%, with Central New York the highest at 88% of respondents thought they had a higher chance of contracting the disease.

When asked if consumers were concerned with contracting COVID-19 themselves, the response was still quite high, with a majority of individuals in each region except Central New York indicating that they were concerned (a “4”) or very concerned (a “5”).

Interestingly, for those regions where over 50% of people were concerned or very concerned about contracting the virus, New York City, the center of the COVID-19 pandemic in New York, was tied with Western New York for the lowest level of concern about contracting, at 51% indicating a “4” or “5”. The Capital Region had the highest level of concern, with 79% of consumers reporting concern that they would be infected. Approximately two-thirds of those in the Hudson Valley and Long Island/Westchester reported concern.
Do you consider yourself at high risk of complications or death if you were to contract COVID-19?

- **Central New York**
  - Yes: 88.2%
  - No: 11.8%

- **Capital District**
  - Yes: 85.7%
  - No: 14.3%

- **Hudson Valley**
  - Yes: 83.3%
  - No: 16.7%

- **Long Island & Westchester**
  - Yes: 69.2%
  - No: 30.8%

- **New York City**
  - Yes: 71.4%
  - No: 28.6%

- **Western New York**
  - Yes: 81.6%
  - No: 18.4%
I am concerned that I may become infected with COVID-19.
Concern regarding the impact of COVID-19 on workforce and availability of PAs.

One critical aspect of community-based long term care is the availability of a workforce. New York is already experiencing a shortage in home care workers and PAs, which has been worsened by COVID-19. Aside from caring about their workers’ well being in general, the risk of a PA passing an infection on to a consumer is high, as PAs are in close proximity and perform intimate tasks for consumers.

If a PA does fall ill, they cannot work their shift. In that case, a consumer must make a decision whether to rely more heavily on informal and unpaid supports and services from family and friends, schedule other PAs to cover the ill PA (which may not be possible due to a lack of overtime reimbursement for overtime), or potentially enter a nursing home against their wishes if none of these options are viable.

Because of the host of potential impacts on consumers, we asked them if they were concerned that their PAs could become infected with COVID-19 as well. Again, outside of Central New York, over 50% of respondents indicated a high level of concern (a “5”) or concern (a “4”) in every region.

The Capital District again reported the largest proportion of a concern at 64.3%. Interestingly, a higher percentage of respondents indicated concern about their PAs contracting COVID-19 than themselves in New York City (53%/51%), Long Island/Westchester (65%/62%), Western New York (53%/51%), and Central New York, where the discrepancy was most pronounced (43%/35%).

This finding merits increased examination, given the high likelihood that an asymptomatic PA would be likely to pass on the virus to a consumer.

The reported concern regarding exposure and infection of PAs likely indicates that consumers, who must plan ahead for emergencies in all cases, worry about PAs they are not currently using during the crisis.
I am concerned my PA(s) may become infected with COVID-19.
Fear of institutionalization in nursing homes due to loss of control.

Nursing homes have been widely covered during the pandemic as dangerous settings: of the 24,400 confirmed deaths from COVID-19 in the state, at least 6,200 have occurred in nursing homes.

For people of color, who are already disproportionately impacted by COVID-19, the prospects are even more grim: 7 of 11 the nursing homes that reported the most deaths of patients from COVID-19 identify at least 46% of their residents as “non-white”.¹

While the majority of nursing home deaths occurred in New York City and the larger New York Metro area, the pattern of racial discrepancies in health outcomes at long term care facilities is consistent statewide.

Given the fact that COVID-19 could impact a consumer’s ability to staff a case, respondents were asked to rate their level of concern, using the same scale as before, about whether they would be placed in a nursing home if their community-based care options became limited. Despite some areas of the state not being concerned about infection themselves, over two-thirds of respondents were concerned or very concerned they would be placed in a nursing home.

This trend was consistent across all regions of New York State, with the Capital District and Hudson Valley reporting the highest percentages at 86% and 83% respectively. New York City, where institutionalization typically occurs at a lower rate than the rest of the state, reported concern at a 71% rate. The lowest regions, Western New York (63% concern), Long Island/Westchester (65%) and Central New York (65%), still reported concern at a rate of nearly two to one.

Concern over being placed in a nursing home has been a pervasive issue since before this coverage, which is one of the reasons CDPA has enjoyed increasing popularity and growth. As consumers and designated representatives are forced to make choices about the number of people entering a consumer’s home, and many PAs declining shifts due to illness and lack of childcare, this fear has taken on a renewed urgency.

I am concerned about being placed in an institution if my options for receiving community care are limited.
Effect of the pandemic on personal assistant recruitment and retention.

A previous report conducted by CDPAANYS, *The High Cost of Low Wages*, found that many consumers are almost constantly recruiting new workers, with approximately one in four advertising for PAs in excess of five times per year. Because of the high rate of PA recruitment in normal circumstances, the survey sought information on how COVID-19 is impacting recruitment and staffing.

It is clear from the data that COVID-19 has had a dramatic impact on consumers’ ability to staff their services. Almost half of consumers in the regions hardest hit by COVID-19 reported having fewer PAs scheduled or working for them. In the Hudson Valley, 50% of respondents indicated they had fewer PAs scheduled or working for them. Consumers in New York City (43%) and Long Island/Westchester (46%) had staffing negatively impacted. Even when areas were not as impacted, consumers saw an impact on their services, with each of the other regions reporting a disruption in scheduling and staffing at least 25% of the time.

### Compared to before the pandemic, I have:

<table>
<thead>
<tr>
<th>Region</th>
<th>The same number of PAs are actively scheduled and working for me.</th>
<th>Fewer PAs actively scheduled and working for me.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital District</td>
<td>28.6%</td>
<td>71.4%</td>
</tr>
<tr>
<td>Central New York</td>
<td>29.4%</td>
<td>70.6%</td>
</tr>
<tr>
<td>Hudson Valley</td>
<td>50.0%</td>
<td>50.0%</td>
</tr>
<tr>
<td>Long Island &amp; Westchester</td>
<td>42.3%</td>
<td>11.5%</td>
</tr>
</tbody>
</table>
|                       |                                                                  | More PAs actively scheduled and working for me.
A snapshot of current PA recruitment activities.

With previous data indicating that many consumers are constantly recruiting, the survey sought to gain a greater understanding of how the COVID-19 pandemic has impacted consumers’ recruitment activities for PAs. Respondents were asked to report whether they are recruiting PAs, and if not, reasons they are not currently recruiting. In every region, at least four in ten consumers report not having a sufficient number of staff. In the Capital District, only one in three consumers reported having a sufficient number of PAs on staff. In Western New York, New York City, and the Hudson Valley, which reported the highest rates of having a sufficient number of PAs, two out of every five consumers reported not having a sufficient quantity of staff.

**Despite the large number of consumers surveyed who reported a shortage of sufficient PAs, the virus is clearly impacting their ability, or desire, to recruit new workers.**

In the Capital Region, half of respondents indicated that they had stopped recruiting because of COVID-19. Similar results were seen in Long Island/Westchester (46% stopped due to COVID-19) and New York City (38%). Indeed, even in the areas reporting the lowest number of individuals who ceased recruiting due to the disease, at least one in four people identified that they were waiting to begin recruiting until the disease passed.

Given the high number of people who put recruiting on hold, combined with the previous concern about infection, it is telling that many are still actively recruiting new PAs. In Central New York, 25% of consumers are actively recruiting. A sixth of consumers in the Hudson Valley are actively recruiting new PAs in spite of the threat posed by the disease, while a seventh of respondents in the Capital District and Western New York are.

Across the state, it is clear that in spite of the overwhelming lack of adequate staffing, COVID-19 is impacting consumers’ ability or desire to recruit.
In New York City, consumers without adequate staffing are foregoing additional recruiting because of COVID at a rate of eight to one. In Long Island/Westchester and the Capital District, three out of every four people who need a worker are not recruiting because of COVID. Even in Central New York, which has the highest percentage actively recruiting workers, only half of those in need of additional staff are recruiting.

**Current PA recruiting activities.**

**Capital District**
- 50.0% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 35.7% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 14.3% I am actively recruiting PAs.
- 5.0% N/A

**Central New York**
- 47.1% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 29.4% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 23.5% I am actively recruiting PAs.
- 5.0% N/A

**Hudson Valley**
- 58.3% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 25.0% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 16.7% I am actively recruiting PAs.

**Long Island & Westchester**
- 46.2% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 42.3% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 11.5% I am actively recruiting PAs.

**New York City**
- 37.5% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 35.3% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 14.3% I am actively recruiting PAs.
- 5.4% N/A

**Western New York**
- 61.2% I am not currently recruiting for more PAs because I am waiting for the pandemic crisis to be over first.
- 24.5% I am not currently recruiting for more PAs because I have enough PAs on staff.
- 14.3% I am actively recruiting PAs.
Access to medical supplies and personal protective equipment (PPE).

Medical supplies and personal protective equipment such as are a critical part of best practices for the provision of many services and play a large role in preventing unnecessary hospitalization and institutionalization in a nursing home. During this pandemic, these materials are even more critical and can be the difference between life and death.

Because of the importance of these materials, we asked survey respondents about their access to medical supplies and their ability to acquire several types of key PPE: face masks, gloves, and hand sanitizer, isopropyl/rubbing alcohol, and sanitizing wipes.

Across all regions, only one in four respondents indicated that they were not concerned about their ability to obtain medical supplies, while approximately half of respondents indicated that they were very or somewhat concerned about their ability to procure these important supplies. Interestingly, when viewed with the inability to obtain specific supplies, the areas with the highest level of concern do not particularly match the areas of greatest shortage, indicating that respondents may be seeing shortages in Upstate regions and are scared they will not be able to obtain enough if the virus strikes the region at an even greater level.

I am concerned I will not be able to obtain medical supplies.
Face masks

On April 12, Governor Cuomo signed Executive Order 202.16, requiring that all essential workers wear masks while interacting with the public to reduce the spread of COVID-19. FIs responded to this requirement by procuring a limited number of masks for consumers’ PAs or paying PAs to obtain their own masks. Despite this, 48% of respondents statewide reported difficulty acquiring face masks, and in New York City, where the virus hit hardest, two out of every three consumers were running low and were scared they would not be able to secure additional masks.

In other regions particularly hard-hit, including the Capital Region, the Hudson Valley, and Long Island/Westchester consumers seem to be more confident in their ability to obtain masks. Even though there was less nervousness, in the Hudson Valley and the Capital Region, two out of every five respondents were running low on masks and unsure if they could obtain more. In Long Island and Westchester, one in three could not find this basic PPE.

After New York City, Western New York is facing the greatest shortage of masks, with sixty percent of consumers reporting a shortage and an inability to find more.
Face masks

Statewide
- I have enough: 52.6%
- I'm running low but have found more: 29.8%
- I am running low and am having difficulty finding more: 11.7%
- I don't use or need face masks: 5.0%

Capital District
- I have enough: 42.9%
- I'm running low but have found more: 23.1%
- I am running low and am having difficulty finding more: 7.1%
- I don't use or need face masks: 50.0%

Central New York
- I have enough: 52.9%
- I'm running low but have found more: 41.2%
- I am running low and am having difficulty finding more: 5.7%

Long Island & Westchester
- I have enough: 30.8%
- I'm running low but have found more: 23.1%
- I am running low and am having difficulty finding more: 8.7%
- I don't use or need face masks: 42.3%

New York City
- I have enough: 64.3%
- I'm running low but have found more: 8.9%
- I am running low and am having difficulty finding more: 21.4%
- I don't use or need face masks: 5.4%

Western New York
- I have enough: 56.5%
- I'm running low but have found more: 8.7%
- I am running low and am having difficulty finding more: 28.3%
- I don't use or need face masks: 6.5%
Gloves

Arguably the most important form of PPE outside of the COVID-19 crisis are gloves. Even when a highly infectious virus is not present, gloves are a minimal best practice that many consumers receive a limited supply of from Medicaid (consumers can receive one box per month from Medicaid).

While it seems that the gloves are not at the same level of shortage that face masks are, it is telling that statewide, only one third of people responding to the survey that use this equipment indicated that they had enough.

Indeed, two out of every five consumers reported not having enough gloves, with an inability to obtain more.

The shortage in gloves seems to be most pronounced in New York City and Western New York, where half of those surveyed indicated that they were running low on gloves and did not know how they could obtain more. In the Capital Region, over 40% of those surveyed were running low without knowing where they could find more, and Central New York, one-third of respondents indicated concern. The Hudson Valley, who reported almost one in five consumers having issues finding new gloves, was the lowest.

![Gloves Chart](image)
Hand Sanitizer & Sanitizing Wipes

With PAs traveling between the consumer’s home and their own home, often on public transportation, PPE such as hand sanitizer, rubbing alcohol, and sanitizing wipes becomes a critical aspect of services for many consumers. Much like the rest of the state, consumers’ ability to find this equipment is proving extremely difficult. Unlike the rest of us, consumers in this area are placed at much higher risk if basic sanitizing equipment cannot be found, particularly those whose disability leads to higher immuno-compromised status.

**Statewide, two out of every three consumers are running low on hand sanitizer with no ability to find more.**

Three out of every four consumers statewide reported shortages of sanitizing wipes. In Western New York, nearly three-quarters of respondents were running low on both hand sanitizer and sanitizing wipes and were unable to find more. In the Hudson Valley, 90% of those surveyed were low on sanitizing wipes with no ability to find more, and seven out of ten were running low on and concerned about finding more hand sanitizer. In Long Island/Westchester, about two-thirds of respondents reported lacking access to additional hand sanitizer or sanitizing wipes.

In New York City, where PAs must often ride crowded public transportation to get to and from consumers houses, two-thirds of people reported being low on sanitizing wipes, and three-fifths were low on hand sanitizer. Indeed, Central New York, who reported greatest access, still is seeing shortages in hand sanitizer among one out of every two people, with seventy percent unable to find sanitizing wipes.

**Hand Sanitizer**
Sanitizing Wipes

Statewide
- I have enough: 71.8%
- I'm running low but have found more: 18.4%
- I am running low and am having difficulty finding more: 8.0%
- I don't use or need sanitizing wipes

Capital District
- I have enough: 78.6%
- I'm running low but have found more: 14.3%
- I am running low and am having difficulty finding more: 7.1%

Central New York
- I have enough: 70.6%
- I'm running low but have found more: 17.6%
- I am running low and am having difficulty finding more: 11.8%

Hudson Valley
- I have enough: 91.7%
- I'm running low and am having difficulty finding more: 8.3%

Long Island & Westchester
- I have enough: 65.2%
- I'm running low but have found more: 17.4%
- I am running low and am having difficulty finding more: 17.4%
New York City
- I have enough: 66.0%
- I'm running low but have found more: 22.6%
- I am running low and am having difficulty finding more: 7.5%
- I don't use or need sanitizing wipes

Western New York
- I have enough: 73.9%
- I'm running low but have found more: 17.4%
- I am running low and am having difficulty finding more: 8.7%
Discussion and Recommendations

The COVID-19 pandemic has had a profound effect on all New Yorkers; however, as Governor Cuomo acknowledged with the implementation of “Matilda’s Law,” the populations most likely to require community-based long term care are facing some of the greatest risk. Consumers across the state are aware of the dangers posed by COVID-19, and a strong majority are tremendously concerned about both their safety and that of their PAs.

While many consumers are always somewhat concerned about the prospect of becoming institutionalized, the extraordinarily high fatality rate in nursing homes is leading to even more widespread fear of losing their freedom and being placed in an institution.

With almost 6,200 people having died in these institutions since the beginning of COVID-19, and over 100 in June\(^2\), as the state begins its reopening process. Given the extent to which consumers are, at the same time they are coping with COVID-19, seeing cuts to funding and eligibility for their program, it would be worth future exploration to determine the extent to which these heightened fears of institutionalization are based on COVID-19, the budget cuts, or a combination of both. However, that was not examined by this survey.

Due to the intimate nature of tasks performed by PAs and the extremely infectious nature of COVID-19, there is a high risk of transmission to consumers if their staff were to fall ill. The data makes it clear that this is impacting consumers’ staffing.

While the data shows us that many consumers have postponed recruiting because of COVID-19, and some are so desperate that they are recruiting in spite of COVID-19, other details are unable to be gathered from the data. Future exploration should seek to learn the extent to which this reduction in staffing is a proactive limitation of human interaction by consumers or the sudden availability of informal supports and which is related to the PA resigning either to limit their exposure or because of a lack of childcare.

Regardless of the rationale, this reduction of staff has led to increased overtime and relying more on informal supports and services. This in turn has placed increased pressure on funding, with agencies facing reimbursement cuts stemming from the $45 million cut to Home Care Workforce Recruitment and Retention funding during the budget at the same time that they are seeing overtime costs dramatically escalate.

As we have watched tragedies unfold in institutions statewide and nationally, and New York’s congregate settings being labeled “death pits” in The New York Times\(^3\), it has become clear that many of these fatalities could have been prevented with adequate PPE. Given that, it is disturbing that our survey shows that consumers and designated representatives are also facing shortages of critical PPE.

With significant percentages of consumers around the state lacking access to critical medical supplies, and two-thirds in New York City worried about access to face masks, it is incumbent on policy makers to ensure that steps are taken to help ensure that seniors and others with disabilities have access to the PPE they require to stay safe.

Based upon the findings of this survey, the Consumer Directed Personal Assistance Association of New York State recommends that the state take several steps that will alleviate the problems posed by or exacerbated by this crisis.

The Legislature should pass A.10427/S.8497 (Kim/Biaggi), which repeals a newly created immunity from liability protection for nursing homes that have experienced deaths of residents on site. While nothing can alleviate the concern that individuals living in the community possess regarding potential need to go to an institution, the repeal of this legislation would restore a sense of normalcy and lower the stress level that the threat of institutionalization poses. By preventing families whose loved one died due to negligence on the part of a nursing home from seeking redress, consumers stress, and potential for complicating factors, is exacerbated.

Policymakers must take steps to ensure that those who need and are entitled to services can access them, so that they can avoid nursing home placement. The number of individuals receiving CDPA who are concerned about being forced into a nursing home as a result of COVID demonstrates that it is imperative that the Legislature pass A.10489/S.8337 (Gottfried/Rivera). This legislation would provide a technical correction to the budget, correcting the means by which Medicaid applicants can access CDPA while their financial “look back” is conducted. Since nursing home data indicates this process will take between 3-6 months, the availability of services is critical.

The language passed in the budget, which allows individuals to privately purchase home care or CDPA and be reimbursed by Medicaid is ineffective, as individuals who meet look-back requirements would be unable to afford these services while awaiting reimbursement. Further, without Medicaid authorization, state law does not even provide for someone to private pay for CDPA services, it only exists in Medicaid. By allowing an attestation of qualification and temporary use while the asset test is occurring, A.10489/S.8337 accurately captures the intent of the language passed in the budget and would further help alleviate fears of institutionalization.

---

Policymakers must restore the $45 million in funding dedicated to worker wages and benefits cut as part of the budget. CDPANYS’ previous study, *The High Cost of Low Wages: 2020*, indicated the extent of problems that consumers were having in hiring workers, even before COVID-19 hit. The survey was clear that COVID-19 merely created the perfect storm to exacerbate this problem, as PAs found out about wage cuts as they were also contending with an increased need for daycare and food. While difficult to know how many PAs quit for this reason, the fact that one in twenty people in New York City were desperate enough for staff that they were inviting potential PAs into their homes during the height of COVID-19 speaks to the level of desperation many felt, and we know that low wages and wage cuts are the source of many of these problems.

**Policymakers must create a new overtime rate for CDPA.** Regardless of whether consumers are using fewer workers out of necessity or choice, it is clear that overtime is escalating drastically as a result of COVID-19. With many agencies receiving less in reimbursement that they provide in overtime wages to a PA making minimum wage, these costs are posing a threat to the agency’s ability to survive.

**Policymakers must ensure the safety of consumers and PAs by ensuring an adequate supply of PPE.** PPE is critical for the safety of consumers, and it is clear from our survey that large numbers of people with disabilities and seniors are unable to secure sufficient amounts of these materials. A.10451/S.08621 (Gottfried/Rivera) would require Medicaid Managed Long Term Care plans (MLTCs) to pay for PPE needed for CDPA, as well as a 90 day emergency PPE inventory for fiscal intermediaries (FIs). Appropriate PPE is crucial to preventing the spread of diseases, and reimbursement for FIs does not include any funding for these materials. While consumers have some access to gloves and masks through Medicaid, the supplies have not been enough to cope with what is needed during the pandemic. By creating a funding stream for these supplies that may only be spent on PPE, the state will help begin to address the problems consumers are having locating and securing PPE.

**Conclusion**

COVID-19 has exacerbated the problems that consumers using CDPA have increasingly faced for years. Whether their fear of being institutionalized, their ability to recruit and retain PAs, or their access to critical medical supplies necessary for both they and their PAs to remain healthy, this pandemic has amplified the issue. To take the steps needed to stabilize the program and allow those who rely on it to continue to safely live in the community, the state must move forward with reforms that guard against the problems this disease has exposed. Improvements to access, eligibility, and funding must be made to protect the short- and long-term health and well-being of consumers and their staff.