



New York Civil Liberties Union  
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April 16, 2020

*Via Electronic Mail OCRComplaint@hhs.gov*

U.S. Department of Health and Human Services  
Office for Civil Rights  
200 Independence Avenue, SW Room 509F  
Washington, DC 20201

Attn: Jocelyn Samuels, Director c/o Centralized Case Management Operations

Re: April 7, 2020 Complaint filed by Disability Rights New York against New York State Governor Andrew Cuomo concerning New York State's Failure to Designate Congregate Care Settings Serving New Yorkers with Intellectual and Developmental Disabilities as Priority Recipients of Personal Protection Equipment

Dear Director Samuels:

The New York Civil Liberties Union (the "NYCLU") writes to you in support of the complaint submitted to your office on or about April 7, 2020 by Disability Rights New York ("DRNY") against the Governor of New York State challenging New York State's failure to ensure that congregate care settings serving New Yorkers with intellectual and developmental disabilities (I/DD) have priority access to essential personal protective equipment (PPE) during the COVID-19 pandemic.<sup>1</sup> The NYCLU writes to highlight the significant danger COVID-19 poses to individuals living and working in congregate care settings without essential PPE.

DRNY has requested that the U.S. Department of Health and Human Services Office for Civil Rights ("OCR") require New York State Governor Andrew Cuomo to ensure that New York State Emergency Management offices prioritize the distribution of PPE to congregate care settings

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<sup>1</sup> The NYCLU, is the New York State affiliate of the American Civil Liberties Union and is a nonprofit, nonpartisan organization with eight chapters, regional offices, and more than 180,000 members and supporters across the state. The NYCLU works to defend and promote the fundamental principles, rights and constitutional values embodied in the Bill of Rights of the U.S. Constitution and the Constitution of the State of New York.

In 1972, the NYCLU, with others, commenced the Willowbrook case, a class action litigation in the United States District Court for the Eastern District of New York in 1972, charging that the State of New York had violated the constitutional rights of the residents of the Willowbrook State School. That action, bearing the caption *New York State Assoc. for Retarded Children v. Cuomo*, Nos. 72 Civ. 356/7, 393 F. Supp. 715 (E.D.N.Y. 1975) (hereinafter the "Willowbrook litigation"), is still pending in the United States District Court before the Hon. Raymond J. Dearie. The Willowbrook litigation was in the vanguard of the civil rights movement for people with disabilities. The NYCLU represents approximately 2200 Willowbrook class members, ranging in age from 45 to over 100 and living in every region of New York State.

serving New Yorkers with intellectual and developmental disabilities (I/DD). The New York State Office for People with Developmental Disabilities (“OPWDD”) has designated the direct service professionals (DSPs) supporting people with I/DD as “essential and integral employees to OPWDD’s provision of services.”<sup>2</sup> Yet DSPs, and the people they support with I/DD, are unable to obtain necessary PPE under New York State’s current Emergency Management policies.

As of April 10, 2020, OPWDD has recorded that 1,898 people with I/DD living in their congregate care settings have become sick with COVID-19 and 173 have died as a result of the infection. The numbers of people with I/DD who have contracted COVID-19 are likely to be significantly under reported. As plaintiffs’ counsel in the Willowbrook case, I receive ongoing reports of Willowbrook class members falling ill and being hospitalized, and in too many cases, dying from confirmed or suspected infection with COVID-19. But OPWDD appears to be tracking only the numbers of people who have laboratory-confirmed cases of COVID-19. OPWDD does not appear to tracking any of the people who have died from COVID-19 without having been tested. New York State is not conducting post-mortem testing or autopsies on people who have died so it is impossible to know the true extent of the spread of this infection and the deaths that result daily from it. Further, OPWDD does not appear to be recording or reporting the numbers of DSPs and other OPWDD staff serving people with I/DD who have become sick and/or died from COVID-19.

OPWDD, Governor Cuomo, and NYSDOH all understand that both people with I/DD and DSPs supporting people with I/DD are at particularly high risk of contracting and spreading COVID-19 because many individuals with I/DD cannot adhere to essential prevention protocols, including wearing a mask, thoroughly and frequently washing hands, and avoiding touching their faces and others. In addition, many DSPs are working in residential settings where up to 14 people with I/DD live in close proximity with one another and with the DSPs. In congregate care settings, DSPs provide intimate care for residents throughout the day, including physical assistance with washing, toileting, dressing, and eating. It is impossible for DSPs to maintain six feet of separation from individual service recipients. The nature of COVID-19 is that many people are contagious when they are completely asymptomatic, and it is critical, as both the federal Centers for Disease Control and Prevention<sup>3</sup> and New York State<sup>4</sup> have come to realize, that all people should be wearing face masks when they are in contact with others in order to prevent asymptomatic spread of COVID-19.

On March 11, 2020, OPWDD, citing then-CDC guidelines and clearly understanding the heightened risks to people with I/DD living in OPWDD-certified residential settings and the DSPs working in close proximity to the residents, advised all state-owned and voluntary providers of congregate settings as follows:

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<sup>2</sup> See Office for People With Developmental Disabilities, *Direct Support Professionals Defined as Essential Employees*, 18 March 2020, <https://opwdd.ny.gov/system/files/documents/2020/03/3.18.2020-direct-support-professionals-defined-as-essential-employees.pdf>. Accessed 15 Apr. 2020.

<sup>3</sup> See Center for Disease Control and Prevention, *Recommendation Regarding the Use of Cloth Face Coverings, Especially in Areas of Significant Community-Based Transmission*, 3 Apr. 2020, <https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/cloth-face-cover.html>. Accessed 15 Apr. 2020.

<sup>4</sup> CDC guidance provides that people who will be within approximately 6 feet of an individual with COVID-19 for a prolonged period of time should wear a facemask when in the same room as a patient who cannot wear a mask themselves. See Center for Disease Control and Prevention, *If You Are Sick or Caring for Someone*, 13 March 2020, <https://www.cdc.gov/coronavirus/2019-ncov/hcp/guidance-prevent-spread.html>. Accessed 15 Apr. 2020. See also New York State Department of Health, *Health Advisory: COVID-19 and the Use of Cloth Face Coverings*, 8 Apr. 2020, [https://oasas.ny.gov/system/files/documents/2020/04/doh\\_covid19\\_clothmasks.pdf](https://oasas.ny.gov/system/files/documents/2020/04/doh_covid19_clothmasks.pdf). Accessed 15 Apr. 2020.

Surgical facemasks should be used by people who have had proximate or close exposure, or who show symptoms of COVID-19 to help prevent the spread of the disease to others. The use of surgical facemasks is also crucial for health workers and people who are taking care of someone in close settings (at home or in a health care facility).<sup>5</sup>

OPWDD has issued additional guidance that when any individual residing in an OPWDD certified-facility is suspected of having COVID-19, either the sick individual should wear a facemask in the presence of others, or staff should wear a mask when in the same room as that individual.<sup>6</sup>

Yet, New York's Emergency Management Offices, such as the one serving New York City, prioritize PPE supplies only to "healthcare providers and facilities that are providing direct patient care in inpatient settings or in specific settings whose staff cannot maintain 6 feet of separation from a patient," such as nursing homes.<sup>7</sup> New York State licensed or certified group homes and other congregate settings for people with I/DD are excluded from this definition and are not prioritized for receiving PPE.

The ADA implementing regulations make clear that illegal discrimination includes providing "an aid, benefit, or service that is not as effective in affording equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement" as that provided to people without disabilities;<sup>8</sup> and utilizing "eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any service, program, or activity."<sup>9</sup> The ADA implementing regulations similarly make it clear that government actors cannot "deny a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different, despite the existence of permissibly separate or different programs or activities."<sup>10</sup>

There is no legitimate reason why congregate care settings for individuals with ID/DD should not be on equal footing with nursing homes. Individuals with I/DD are at least as equally vulnerable as those in nursing facilities and these individuals and the DSPs supporting them should

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<sup>5</sup> *OPWDD Guidelines for Implementation of Quarantine and/or Isolation Measures at State Owned and Voluntary Providers in Congregate Settings*, Office for People With Developmental Disabilities, 11 March 2020, [https://opwdd.ny.gov/system/files/documents/2020/03/opwdd-guideline-for-containment\\_3-11-20.pdf](https://opwdd.ny.gov/system/files/documents/2020/03/opwdd-guideline-for-containment_3-11-20.pdf). Accessed 15 Apr. 2020.

<sup>6</sup> See Office for People With Developmental Disabilities, *Revised Staff Guidance for the Management of Coronavirus (COVID-19) in Facilities or Programs Operated and/or Certified by Office for People With Developmental Disabilities*, 25 March 2020, [https://opwdd.ny.gov/system/files/documents/2020/04/4.15.2020-opwdd\\_covid19\\_staffguidance\\_0.pdf](https://opwdd.ny.gov/system/files/documents/2020/04/4.15.2020-opwdd_covid19_staffguidance_0.pdf). Accessed 15 Apr. 2020.

<sup>7</sup> See e.g., *2020 Advisory #8 COVID-19 Update for New York City*, New York City Department of Health and Mental Hygiene, dated 20 March 2020, <https://www1.nyc.gov/assets/doh/downloads/pdf/han/advisory/2020/covid-19-032020.pdf>. Accessed 15 Apr. 2020.

<sup>8</sup> 28 C.F.R. § 35.130(b)(1)(iii).

<sup>9</sup> *Id.* See also 28 C.F.R. § 35.130(b)(8).

<sup>10</sup> 28 C.F.R. § 35.130(b)(2). The ADA implementing regulations make it clear that government actors cannot "directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity's program with respect to individuals with disabilities; or (iii) That perpetuate the discrimination of another public entity if both public entities are subject to common administrative control or are agencies of the same State." 28 C.F.R. § 35.130(b)(3).

have equal access to PPE.<sup>11</sup>

New York's exclusionary policy concerning priority allocation for receipt of PPE puts individuals with I/DD and their DSPs at serious risk of harm and death. Many people with I/DD have weakened immune systems that would require additional treatment time and medical resources and many people with I/DD have other co-occurring medical conditions that put them at very high risk of death if they should contract COVID-19. Use of PPE in congregate settings will significantly reduce the number of residents requiring hospital beds, medical intervention, and other valuable resources. Use of PPE in congregate settings will also substantially reduce the number of people with I/DD who will die from COVID-19. State-operated settings and settings operated by not-for-profit private providers are forced to compete in the open market place to source and purchase PPE for their staff and the residents in the homes these providers operate – where those supplies are simply unavailable.<sup>12</sup>

New York State has failed entirely to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability” and has failed to demonstrate “that making [any] modifications would fundamentally alter the nature of the service, program, or activity.”<sup>13</sup>

Similarly, New York's priority allocation system governing receipt of PPE violates the implementing regulations of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794. Section 504 also prohibits discrimination against people with disabilities by entities that receive federal financial assistance. New York State is a recipient of federal financial assistance, and has engaged in unlawful discrimination under Section 504, including:

- Excluding from participation in, denying the benefits of, or otherwise subjecting to

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<sup>11</sup> Indeed, “more than 156 people with developmental disabilities in group homes have already died. The architecture and the nature of developmental disabilities are contributing factors. The quarters are much more cramped than in nursing homes, and there are many fewer yards of cubic air for COVID-19 to spread out and become less deadly.” Van Ornum, William, *Back to Willowbrook: The risk of group homes in the age of coronavirus*, New York Daily News, 13 April 2020, <https://www.nydailynews.com/opinion/ny-oped-back-to-willowbrook-20200413-a3k2haaxyvbsziszkwceira-story.html>. Accessed 15 Apr. 2020.

<sup>12</sup> The “low point” came when the New York City Office of Emergency Management told AABR that they were “below the priority level to receive PPE,” Traynor said “We must prioritize ensuring the availability of protective equipment for health care workers at this time,” health department spokesman Patrick Gallahue told CNN. “The City’s health care system is facing a severe shortage of masks, gloves, and other key supplies that are needed to protect health care workers treating critically ill patients in our hospitals. Local hospitals may run out of critical supplies within weeks at the current rate.” See Cooper, Aaron, *New York nonprofit for developmentally disabled struggling for help with coronavirus*, CNN, 21 March 2020, <https://www.cnn.com/2020/03/21/us/ny-group-homes-coronavirus/index.html>. Accessed 15 April 2020. Mike Alvaro, treasurer of New York Disability Advocates, said that it was a struggle to ensure “that the face masks and the gowns and gloves are there,” and that already stretched budgets were being tested. See Hakim, Danny, *It’s Hit Our Front Door: Homes for the Disabled See a Surge of Covid-19*, New York Times, 8 Apr. 2020, <https://www.nytimes.com/2020/04/08/nyregion/coronavirus-disabilities-group-homes.html?searchResultPosition=1>. Accessed 15 April 2020. See also Watson Suepel, Celia, *Health care workers provide support, compassion to those with disabilities during pandemic*, Daily Freeman, 14 April 2020, [https://www.dailyfreeman.com/news/local-news/health-care-workers-provide-support-compassion-to-those-with-disabilities-during-pandemic/article\\_7854a3be-7b5f-11ea-b942-4f1a8caa2e83.html](https://www.dailyfreeman.com/news/local-news/health-care-workers-provide-support-compassion-to-those-with-disabilities-during-pandemic/article_7854a3be-7b5f-11ea-b942-4f1a8caa2e83.html). Accessed 15 April 2020, reporting that even the ARC, one of the largest and best-funded service providers in New York State, is has run out of personal protective equipment. “We’re doing everything we can to purchase it,” said Priest. “We’ve just launched a COVID-19 relief funding page.” They’re asking people to donate masks (including homemade masks), gloves, and cash.

<sup>13</sup> 28 C.F.R. § 35.130(b)(7).

discrimination on the basis of disability.<sup>14</sup>

- Denying qualified persons with a disability the opportunity to participate in or benefit from the aid, benefit, or service.<sup>15</sup>
- Affording qualified persons with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others.<sup>16</sup>
- Limiting individuals with a disability in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.<sup>17</sup>
- Using criteria or methods of administration that have the effect of subjecting qualified persons to discrimination on the basis of disability, or that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of program or activity with respect to persons with disabilities.<sup>18</sup>
- Failing to make reasonable modifications in policies, practices, or procedures, when the modifications are necessary to afford goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities.<sup>19</sup>

Accordingly, the NYCLU agrees with DRNY that Governor Cuomo's refusal to ensure that congregate settings that serve people with ID/DD are prioritized for PPE violates Title II of the ADA and its implementing regulations and Section 504 of the Rehabilitation Act of 1973.

Because these issues are of critical importance to New Yorkers with I/DD, and the DSPs and other staff who support people with I/DD, during the COVID-19 pandemic, we urge OCR to act expeditiously with respect to DRNY's complaint and to require Governor Cuomo to take immediate steps to ensure congregate care settings serving individuals with ID/DD are prioritized, statewide, for the receipt of PPE.

Thank you for your consideration of our support of DRNY's complaint.

Respectfully submitted,



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<sup>14</sup> 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.4(a) and 84.52(a)(1); 28 C.F.R. § 41.51(a).

<sup>15</sup> 45 C.F.R. § 84.4(b)(1)(i); 28 C.F.R. § 41.51(b)(1)(i).

<sup>16</sup> 45 C.F.R. §§ 84.4(b)(1)(ii) and 84.52(a)(2); 28 C.F.R. § 41.51(b)(1)(ii).

<sup>17</sup> 45 C.F.R. §§ 84.4(b)(1)(vii) and 84.52(a)(4); 28 C.F.R. § 41.51(b)(1)(vii).

<sup>18</sup> 45 C.F.R. §§ 84.4(b)(4) and 84.52(a)(4); 28 C.F.R. § 41.51(b)(3).

<sup>19</sup> *Henrietta D. v. Bloomberg*, 331 F.3d 261, 273–76 (2d Cir. 2003).

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