

# REPORT TO THE GOVERNOR: KEEP THE PROMISE.

Community-based housing for people with intellectual and  
developmental disabilities

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## Keep the Promise.

New York State citizens with intellectual and developmental disabilities (I/DD) are waiting for their own homes. Thousands are in need of immediate residential housing. Aging family members and lack of residential housing development have resulted in a housing crisis for people with I/DD.

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## Executive Summary

**A Housing Crisis for People with I/DD.** Of the 11,000 New York State citizens with intellectual and developmental disabilities (I/DD) waiting for their own homes, thousands are in immediate need of residential opportunities. In addition, the wait list is opaque. People with I/DD and their families do not have access to the list or the information therein. During the 2016-17 legislative session, a coalition formed to advocate for funding to provide direct support professionals (DSPs) with a living wage. As a result, Governor Andrew Cuomo and legislative leaders recognized the need for this additional funding. **However, there is another critical issue facing New York State, and we are calling on Governor Cuomo to guarantee the right of people with I/DD to live in the community.**

**Keep the Promise.** New York State's history of providing community-based housing for people with I/DD began with the signing of the Willowbrook Consent Decree in 1975. Governor Hugh Carey guaranteed the right of people with I/DD to live in the community. Currently, the only option for many citizens with I/DD is to reside at home with their parents, a living arrangement that can be as restrictive as an institutional environment if the caregiver is unable to provide community integration.

**The Current Situation.** The state has failed to provide a way for families to plan for the future as home caregiving becomes difficult or impossible, putting both the families and the individuals with I/DD at risk. In recent years, a shortage of residential opportunities for all but emergency cases has grown. When the state offers housing almost solely on an emergency basis, the guarantee of a most appropriate, least restrictive home that incorporates choice is impossible. In response to this crisis, family members, concerned citizens, former government officials, and others recently formed the *Keep the Promise Family Coalition*.

**The 2016 Report to the Legislature: Residential Request List (The Report) demonstrates that the development of new residential opportunities for people with I/DD is lagging far behind the demand.** According to this report, 62% of responders said their preference was placement in a residential setting with services provided by an agency, but opportunities, with the exception of the most critical situations, do not exist to support this need. According to the Office for People With Developmental Disabilities (OPWDD), the people who are on non-emergency lists include individuals living in situations that may present a significant risk to their well-being. There is virtually no chance for these individuals to receive homes of their own. While the FY 2017-18 budget funds the initial phases of a living wage for DSPs, the budget provides no meaningful progress toward increasing residential opportunities for individuals on the residential wait list.

**To Restore the Promise, the Governor Must Do the Following:** 1) Transparently assess the number of persons who have requested or need residential services and keep a wait list with a publicly available summary; 2) streamline the eligibility process so that persons on the wait list can have their eligibility rapidly assessed and established; and 3) provide capital and operating funding to establish as many new residential opportunities as are necessary to meet the needs of New Yorkers with I/DD.

## A Housing Crisis for People with I/DD

**New York is facing a housing crisis for people with intellectual and developmental disabilities (I/DD). Of the 11,000 New York State citizens with I/DD waiting for their own homes, 3,000 are in need of residential opportunities.**<sup>1</sup> Today, the length of the wait list for appropriate housing is not even fully known, except that we do know that a relatively limited number of people who recently responded to a state survey have been waiting about seven years.<sup>2</sup> In addition, the wait list is opaque. People with I/DD and their families do not have access to the list or the means to understand their place and priority on the list. These are people with autism, intellectual disabilities, cerebral palsy, Down syndrome, and other neurological impairments.

During the 2016-17 legislative session, families, direct support professionals (DSPs), self-advocates, and voluntary providers formed a coalition to advocate for funding to provide DSPs with a living wage. Because of the coalition's relentless efforts, Governor Andrew Cuomo and legislative leaders recognized the need for this additional funding. Families who depend on DSPs to care for their loved ones are grateful. There is, however, another critical issue facing New York State and **we are calling on Governor Cuomo to keep the promise made in 1987 with the closing of Willowbrook to guarantee the right of people with I/DD to live in the community.**

Previously, New Yorkers with I/DD could rely on the state to provide housing opportunities for individuals living at home with their families, including the right to choose among the least restrictive and most appropriate homes within the community. Although Governor Cuomo's Olmstead Cabinet declared that "New York is reclaiming its leadership role in serving people with disabilities," and that these individuals have the right to receive supports in integrated settings, his administration has failed to provide enough funding for these opportunities.<sup>3</sup> **Indeed, his own Office for People With Developmental Disabilities (OPWDD) reports that the urgent need for residential opportunities for people with I/DD exceeds the supply**<sup>4</sup>. Families are baffled that the administration has not responded to the crisis documented by OPWDD.

**In response to this crisis, family members, concerned citizens, former government officials, and others recently formed the *Keep the Promise Family Coalition* to petition the governor and the legislature to uphold the promise made over thirty years ago by Governor Mario Cuomo with the closing of Willowbrook State School.<sup>5</sup> That promise, enshrined on a plaque unveiled at that closing, was clear in its proclamation of a "commitment to provide an extensive and comprehensive program of community living opportunities for its citizens with mental retardation and developmental disabilities."**

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<sup>1</sup> The Report, p. 13. (2,976 responders out of 4,462 total expressed a need.)

<sup>2</sup> The Report, p. 9.

<sup>3</sup> Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting.

<sup>4</sup> For example, The Report indicates that 1,800 individuals expressed a desire to live in an agency-staffed home (pg. 13), but the state anticipates having only 1,400 opportunities in 2016-17 (pg. 21).

<sup>5</sup> Willowbrook Consent Decree, 25th Year: College of Staten Island President's Award Ceremony.

## Keep the Promise

**New York State’s history of providing community-based housing for people with I/DD began with the closing of the Willowbrook State School on Staten Island.** In 1972, individuals, parents, and NYSARC sued the state in federal court, challenging the inhumane conditions imposed on people with I/DD. In 1975, Governor Hugh Carey signed the Willowbrook Consent Decree, thereby settling the suit. This decree mandated that New York State develop and operate a broad range of non-institutional community facilities and programs.<sup>6</sup>

**Closing Willowbrook in 1987 was a transformational event that redefined the lives of individuals with I/DD. Living in the community and having social relationships within a diverse group became the expectation.** Individuals with I/DD and their families, governors, state agencies, and the New York State legislature joined in making the promise of a life integrated with the community a reality. In the late 1990s, Governor George Pataki reaffirmed the promise by enacting legislation called New York State Cares. This legislation successfully designed out-of-home residential opportunities for those seeking them. The state is breaking this promise by continuing to force people to wait for years under the current plan of development to receive new homes. People with I/DD are facing uncertain futures and are losing hope.

### The Current Situation

The *2016 Report to the Legislature: Residential Request List* (The Report) demonstrates that in many cases, family caregivers are experiencing health and stress-related issues due to age. OPWDD surveyed almost 4,500 of the 11,000 individuals who had previously expressed interest in residential opportunities.<sup>7</sup> In that report, almost half of caregivers are over the age of

60 and two-thirds are experiencing health issues themselves. The state has failed to provide a way for families to plan for the future as home caregiving becomes difficult or impossible, putting both the families and the individuals with I/DD at risk. As caregivers become unable to provide access to the community themselves, living in a family home can become as restrictive as institutionalization.

Caregiving Falls on the Shoulders of Aging Parents	
Reality of Caregivers	
48%	caregiving involves help with "almost all basic activities"
86%	caregivers are parents (54% are single parents)
62%	caregivers are themselves experiencing health issues
46%	caregivers are over the age of 60

**Note: As family caregivers age, the quality of care of individuals with I/DD may become difficult to manage. Source: the Report, p. 11.**

<sup>6</sup> Willowbrook Consent Decree.

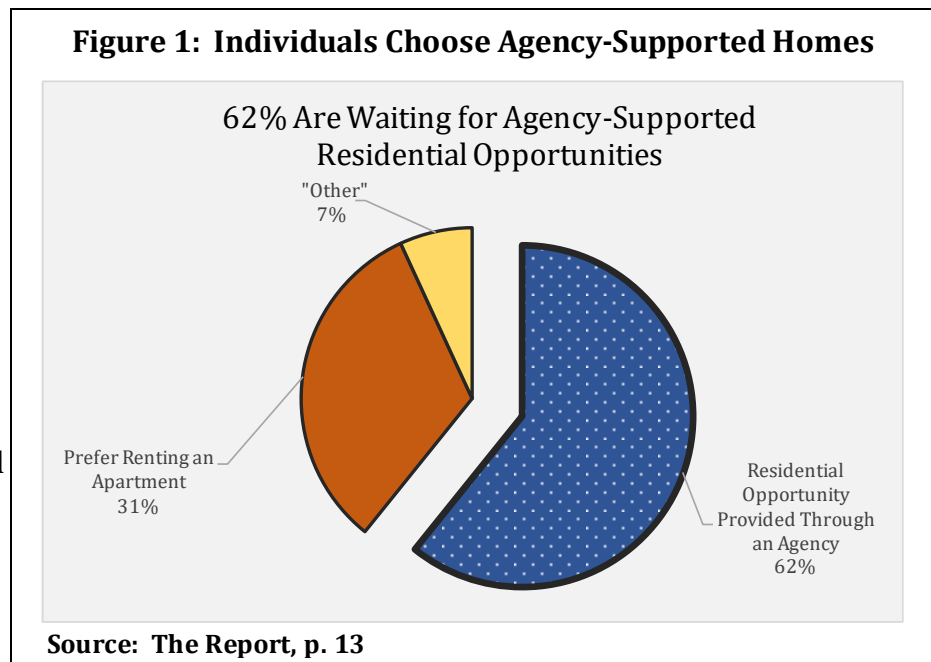
<sup>7</sup> The Report, p. 6.

Furthermore, resources have eroded under the Cuomo Administration, which has neglected to develop new residential opportunities outside of the family home. In one documented case, OPWDD informed an aging family that their son would not receive a residential opportunity. In this case, Joan was 81 and suffered from emphysema and heart trouble. She requested placement for her 57-year-old son Michael (a person with I/DD and a seizure disorder who had never lived away from his family).<sup>8</sup> Joan learned that there was an opening in a local residential facility and requested it because Michael had friends living there. She knew he would transition better with her support. OPWDD, however, did not see Michael as an emergency priority and refused her request. Joan died of a heart attack two months later. Michael received an emergency residential opportunity then, but the transition was traumatic. Michael's extreme stress led to behavioral problems requiring police intervention and emergency room visits.<sup>9</sup> It is legally wrong and morally repugnant that the only way for citizens of New York State with disabilities to realize their civil rights and have homes of their own is to wait for their parents to die.

**Federal law requires states to offer choice in residential opportunities.** In 2014, the Centers for Medicare & Medicaid Services announced new federal regulations mandating that states provide residential offerings for people with I/DD that allow options to “be chosen by the

individual from among residential and day options” and include the least restrictive appropriate placement.<sup>10</sup> The Cuomo administration has not afforded many individuals their right to have a say where they live and with whom they live. Individuals with I/DD face a “take it or leave it” emergency

placement in which “most appropriate,” “least restrictive,” and “choice” are simply not available. The Report states that 62% of responders would choose to live in a residential setting with services provided by an agency, but a significant number of those New Yorkers will face an emergency placement with no option for choice due to limits in availability (Figure 1). Additionally, there is no allowance for a smooth transition to a new living arrangement when a family becomes aware of a change in caregiver wellness. The state cannot meet this basic need under current conditions.<sup>11</sup>



<sup>8</sup> Surnames are omitted to protect the confidentiality of the aforementioned persons.

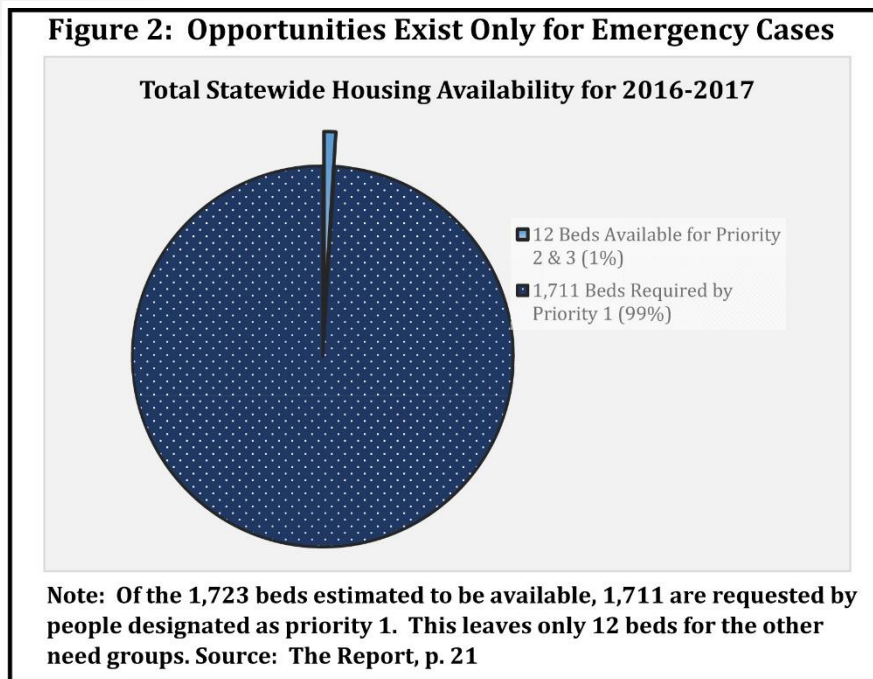
<sup>9</sup> Goldberg, Dan.

<sup>10</sup> “The Medicaid Home and Community Based Services Settings Rules,” p. 3.

<sup>11</sup> Furthermore, it is a basic tenet of the law that parents are not legally obligated to support their children beyond age 21, although many parents of children with I/DD may do so out of a lack of alternatives.



The Report states that openings in residences are virtually nonexistent for individuals whose situation is labeled as less than an emergency. Consequently, adult citizens with



I/DD have no choice other than to live at home with their parents. Only 1% of available residential opportunities are available to those with non-emergency needs (Figure 2). This illustrates a severe lack of choice for those seeking new homes. The current options through OPWDD prioritize at-home supports over the development of alternative residential living opportunities. This emphasis

eliminates choice, however, for those individuals seeking homes of their own because the alternatives are not being developed to meet that need. In addition, aside from choice, at home supports are not appropriate for every individual due to the differences in needs and abilities of people with I/DD.

The *Progress Report to the Legislature: Update on Progress in Key Areas of Transformation* redefines the three priority categories.<sup>12</sup> Categories are labeled as Emergency Need, Substantial Need, and Current Need.<sup>13</sup> While residential opportunities may exist for people who are Emergency Need, practically speaking, no opportunities exist for those who are Substantial Need and Current Need. The failure by the state to provide required state funding to meet this obligation through increased placements with voluntary providers does not save the state money. In fact, placement in state-operated facilities is much more expensive and failure to provide stable housing can lead to increases in homelessness, more hospital and nursing home placements, and other costly medical care.

**Current state funding cannot meet the need for additional housing for those people whose parents are becoming too elderly to care for them.** According to OPWDD, of the 4,500 people surveyed in 2016, the almost 1,400 people who are on the Substantial and Current Need lists include individuals living in situations with aging caregivers or caregivers with failing health.<sup>14</sup> The 2017-18 state budget does not represent meaningful progress toward increasing residential opportunities for individuals on the wait list. It describes enough residential opportunities in the next three years to provide housing for 4,900 individuals

<sup>12</sup> "Progress Report to the Legislature: Update on Progress in Key Areas of Transformation," pp. 5-6.

<sup>13</sup> The definition of priority groups is as follows: Formerly known as Priority One, Emergency Need (people who are at risk of having no permanent place to live or whose health and safety are at risk), formerly known as Priority Two, Substantial Need (people whose caregivers are unable to continue to give care, as well as those transitioning from a residential school, a developmental facility, or a skilled nursing facility), and formerly known as Priority Three, Current Need (people who have a current need for housing but whose need is neither an emergency nor substantial).

<sup>14</sup> The Report, p. 23.

living at home who require a certified residential opportunity, and 1,400 individuals living at home who require a more independent supportive housing opportunity.<sup>15</sup> These do not represent new openings; these are openings anticipated due to death or transfers. While this appears to be a growth in opportunities, it actually represents normal anticipated turnover. People who have not yet suffered the consequences of a tragic event will not have their needs met.<sup>16</sup>

## Restore the Promise

**In order to restore the promise, the governor must do the following:**

- 1) Transparently assess the number of persons who have requested or need residential services and keep a wait list, including a publicly available summary.**
- 2) Streamline the eligibility process so that persons on the wait list can have their eligibility rapidly assessed and established.**
- 3) Provide capital and operating funding to establish as many new residential opportunities as are necessary to meet the needs of New Yorkers with I/DD.** The residential opportunities, which must be operational within five years, must appropriately meet the needs of the individual and guarantee that the state fund those opportunities in accordance with the level of need and the choice of each individual. This new residential development must be separate from the development needed to ensure sufficient capacity to convert large residences, which may no longer be permissible under new federal rules, to smaller community-integrated residences. This will require additional funding, both operating and capital, to meet this separate obligation.

## Conclusion

**We are in a crisis, but there is a solution.** Governor Cuomo recognized the crisis that is threatening the quality of service to individuals with I/DD caused by excessive employee turnover and vacancies resulting from the inadequate wages paid to DSPs and committed funding to take the first step toward providing DSPs with a living wage. We need a new commitment by the governor, with the appropriate funding, to restore the promise and solve this problem. New York upheld the promise to provide housing made thirty years ago because New York recognizes that people with I/DD are citizens and are entitled to live in decent and appropriate housing of their choosing. As Governor Andrew Cuomo has said, “People with disabilities have the right to receive services and supports in settings that do not segregate them from the community; it is a matter of civil rights.”<sup>17</sup> We need the governor to be true to his words and restore the promise.

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<sup>15</sup> “Meeting the Residential Needs of Those Living at Home,” Provider Association Meeting. *Office for People with Developmental Disabilities*.

<sup>16</sup> OPWDD’s own Residential Request List (Feb. 2016) reported that its projected residential opportunities for 2016-17 would result entirely from “capacity in the existing system.”

<sup>17</sup> “Report and Recommendations of the Olmstead Cabinet: A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Settings,” p. 2.



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