

# Reimagining. Reorienting. Revolutionizing.

*A strategy to improve respite access and outcomes in our region*

## Introduction

More than 4,000 families of people with intellectual and developmental disabilities receive respite services in Region 1 of the New York State Office for People with Developmental Disabilities (OPWDD).<sup>1,2</sup> At least 2,600 more families in the region are waiting for respite services that the current system is unable to deliver.<sup>3</sup> We are proud to present a strategy to broaden access to respite services<sup>4</sup> in Region 1 while improving outcomes.

## Current State

More than 4,100 individuals in the 17 counties of OPWDD Region 1 currently receive respite services. These services are provided by 56 not-for-profit providers, as well as OPWDD's state-operated respite program.

Still, about 1,600 people in Region 1 have unmet day or evening respite needs, and approximately 1,500 people have unmet overnight respite needs.<sup>5</sup> A 2016 report from the OPWDD Region 1 Regional Office states, "Our inability to provide services on a timely basis, particularly at the highest levels of need, is creating significant pressures on other parts of our own delivery system and other systems of care."<sup>6</sup>

Why is the system unable to keep up with respite needs? In a statewide OPWDD survey, insufficient staffing was cited as a major obstacle by 75% of provider agencies.<sup>7</sup> Similarly, service coordinators in Region 1 reported staffing shortages as the top reason for the high level of unmet respite need.<sup>8</sup>

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<sup>1</sup> OPWDD Region 1 consists of New York State's 17 westernmost counties: Allegany, Cattaraugus, Chautauqua, Chemung, Erie, Genesee, Livingston, Monroe, Niagara, Ontario, Orleans, Schuyler, Seneca, Steuben, Wayne, Wyoming and Yates.

<sup>2</sup> Source: OPWDD Region 1 Regional Office

<sup>3</sup> Ibid.

<sup>4</sup> For clarity's sake, this document assigns the name "respite" to a number of OPWDD community-based services that provide caregiver relief while helping individuals with I/DD to live the fullest possible lives; these services include Waiver Respite in a variety of settings from private homes to community sites, Family Support Services Respite that is not HCBS Waiver-funded, Community Habilitation, and certain Self Directed services.

<sup>5</sup> Ibid.

<sup>6</sup> Source: *Report to Commissioner Delaney: Status of Respite Services in OPWDD Region One*, OPWDD Region 1 Regional Office, 2016.

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

These findings are validated by third-party research at the national and state levels. According to a 2016 statewide survey, I/DD providers are facing an 11.1% vacancy rate for direct support professionals – a 43% increase from 2014.<sup>9</sup> The turnover rate in these positions is 24.8% -- a 30.5% increase from 2014. As a result, overtime hours increased 33.8% from 2014 to 2016.<sup>10</sup> And the problem is unlikely to abate. A national study forecasts a 48% increase in demand for direct care workers across the nation from 2010-2020.<sup>11</sup>

The need for specialized respite training is another concern identified by a provider workgroup assembled by the OPWDD Region 1 Regional Office. Provider agencies have come to understand that respite requires a unique set of competencies. Standard employee training programs geared toward group home staff simply do not prepare respite workers for the job they face. In fact, a residential-focused orientation program can chase away new hires who wish to specialize in respite.

As the worker shortage intensifies, those who suffer the effects are families and individuals – a disproportionate number of whom are children.

People Receiving Respite in Region 1, by Age Group <sup>12</sup>

Under age 10	13%	Age 20 and Under	58%
Ages 10 – 20	45%		
Ages 21 – 30	25%	Ages 21 – 40	33%
Ages 31 – 40	8%		
Ages 41 – 50	5%	Ages 41 – 60	8%
Ages 51 – 60	3%		
Ages 61 – 70	1%	Over Age 60	1%
Ages 71 – 80	0%		
Over Age 80	0%		

As the chart above shows, 58% of respite currently delivered in Region 1 is used by families of individuals under age 21. Statewide, the 5-to-21 age range makes up 45% of the total unmet need, while in Region 1, that age group makes up 59% of unmet need. The discrepancy is likely due to the fact that Region 1 has the lowest level of residential school placements in the state. Given the high level of respite usage by individuals under the age of 21, after-school respite is one of the most-used forms of respite in the region.

In response to a mandate from the State Legislature, in 2016 OPWDD conducted an extensive survey of families on the waiting list for certified residential placements. Some key findings<sup>13</sup>:

- 86% of family caregivers reported that they, not outside organizations, provide most of the care to their loved ones.

<sup>9</sup> Source: BFair2DirectCare Coalition Provider Survey, 2016.

<sup>10</sup> Ibid.

<sup>11</sup> Source: PHI National Care Gap Study, 2016.

<sup>12</sup> Source: *Report to Commissioner Delaney: Status of Respite Services in OPWDD Region One*, OPWDD Region 1 Regional Office, 2016.

<sup>13</sup> Source: *Report to the Legislature: Residential Request List*, OPWDD, 2016.

- 61% of family caregivers reported that they are experiencing health and/or stress-related issues that make it difficult to continue providing care to their loved ones.
- 61% of family caregivers said they would like to keep their loved ones at home if they had more services and supports to help them do it.
- 53% of family caregivers requested more respite services and 54% requested more day services to help their loved ones stay at home longer.
- While a majority of family caregivers express interest in certified group home placements, this may be due to a lack of awareness about other options. Over 90% of respondents are interested in learning about housing options other than 24/7 certified settings.

New York State’s Residential Request List includes 11,000 individuals who have asked for residential supports and have not yet received them.<sup>14</sup> And we know that supports and services to keep someone living at home is much less expensive than 24/7 group home placements.

Yet OPWDD’s investment in community-based programs such as respite has been disproportionately low vis-à-vis the funding of certified residential programs. Consider this: 78% of New York State’s total I/DD spending in 2015 went toward housing programs and related services, while just 5% went into family support and another 5% was dedicated to supported living and personal assistance.<sup>15</sup> These figures are astonishing in light of the fact that 63% of New Yorkers with I/DD – nearly 200,000 people – were living with a family caregiver in 2015.<sup>16</sup> It is past time to make the home- and community-based infrastructure more robust and effective.

OPWDD does have a funding stream called Family Support Services, which supports programs that help families to care for loved ones with I/DD who live at home. While this funding helps to fill the service gap, resources are limited. Relying on Family Support Services to meet all of the unmet respite needs in the region is not a viable option, as most Family Support Services programs are already running at capacity with extensive waitlists.

So, demand is growing. Families and individuals hang in the balance. And as OPWDD eyes a shift to managed care in four short years, urgent change is now required. It is time to knock down the systemic barriers that keep the respite delivery system from reaching its potential.

One long-standing obstacle has already been removed. A recently concluded agreement between New York State and the federal government includes a fee schedule that pays providers more reasonably for respite services; it also allows individuals who are self-directing their services to spend more resources on caregiver relief.

<sup>14</sup> Source: *Report to the Legislature: Residential Request List*, OPWDD, 2016.

<sup>15</sup> Source: *The State of the States in Developmental Disabilities*, University of Colorado, 2017.

<sup>16</sup> *Ibid.*

Now, three remaining hurdles must be addressed:

- The struggle to recruit, develop and keep skilled respite workers as a distinct component of the direct care workforce
- The need to equip respite workers with the tools to do the job effectively so they can build bonds of trust with individuals and families
- The inefficient, duplicative onboarding process that kicks in when a respite worker wants to work for more than one provider at a time.

No single provider can solve these issues on its own. Now is not a time for half-measures or tinkering around the edges. What we propose instead is a system-wide strategy to deliver the best, most accessible respite services possible. In the process, we intend to create a model that can be replicated across New York State and beyond.

### Coalition

Consistent with the collaborative nature of Region 1, a group of respite providers has been working closely with OPWDD Region 1's Regional Office to develop a shared strategy for improving access to respite services. Members of the coalition include:

- The Arc Erie County New York
- Aspire of WNY
- Cantalician Center
- Community Services for the Developmentally Disabled
- Empower (formerly Niagara Cerebral Palsy)
- Heritage Christian Services
- New York State Office for People with Developmental Disabilities (Region 1)
- People Inc.
- SASI
- The Summit Center
- University at Buffalo School of Social Work

OPWDD's state-operated programs are participating in this coalition, and will benefit from its work. For example, the Family Care Department provides community-based residential housing in private homes and provides respite to natural families. Family Care trains respite workers to offer support in Family Care providers' homes, by helping families to deal with emergencies, attend medical appointments and go on vacation. By participating in this initiative, the Family Care program will be better able to assist families in Region 1.

## A Strategy to Improve Respite in Region 1

The coalition described above has developed a three-pronged strategy to improve respite access and outcomes in Region 1:

- Reimagining the respite workforce and reducing onboarding duplication
- Reorienting the learning and development process for respite workers
- Revolutionizing the matching process to improve outcomes and reduce time to service

All respite providers in Region 1 will be invited and encouraged to participate in all three phases of this initiative. Our intent is to create system-wide solutions. Therefore, participation will not be exclusive to the organizations that are currently part of this coalition.

Coalition members envision the hiring of a project manager for a three-year period. The project manager will coordinate efforts among all participating organizations, including vendors. The employer of record will be determined at a later date. Also, we are having positive discussions with the University at Buffalo School of Social Work about engaging students in the project as a field placement.

### **Solution 1: Reimagining the respite workforce and reducing onboarding duplication**

Given the staffing shortage detailed above, it is no longer possible for providers to cover respite cases primarily with staff from certified residential sites. While that scenario used to be the norm for many providers, the shortage of direct support professionals in group homes has made it impossible to continue “robbing Peter to pay Paul.”

Providers are reimagining the respite workforce as a distinct group of direct support professionals, apart from those who work in group homes. We need a new approach, informed by the evolving “gig economy,” in which we identify groups of potential part-time respite workers. These new workers may have a limited number of hours to offer each week, but if enough of them join the respite workforce, they can make a huge dent in the backlog of unfilled cases.

Who are these potential respite workers? Our coalition intends to identify a set of ideal constituencies to target for recruitment into the respite workforce. At the outset, we believe the pool includes retirees, college students, and people who are already employed elsewhere but are interested in earning additional income. We plan to engage a marketing communication firm to develop an integrated campaign that will reach these constituencies with compelling recruitment messages.

This strategy shift requires a mindset shift. We will be recruiting workers to work for the individual and the family, rather than for the provider agency. “Gig economy” workers can be expected to migrate from one agency to another as the need warrants. Some may choose to work for more than one agency at a time – in fact, to some extent this is already happening today.

This flexibility will be essential if we have any hope of reducing the time that families wait for respite services. Today, some people sit on waiting lists for two or more years before receiving respite. So, what happens when a family is truly in crisis?

Imagine a single mother caring for a child with an intellectual disability. The mother learns that her parent is critically ill in the hospital. She wants to visit the hospital, but she cannot take her child with her because of behavioral issues. She does not have other family to rely on, so she frantically calls the agency that supports her child, looking for overnight respite services that would allow her to spend the night at the hospital. The agency has a respite bed but cannot find staff on short notice. Meanwhile, a trained respite worker from another agency has time to work that night – but that agency’s respite beds are already full.

Currently, it is impossible for a worker from one agency to quickly fill a need at another agency. Why? Because OPWDD’s regulatory structure has not yet evolved with the workforce. When a respite worker – or any direct support professional – joins an agency, s/he has to go through a background check, fingerprinting and training with that agency – even if s/he has already done so with another agency. This process can take days or even weeks to complete. Along with the inconvenience to the worker, it adds time and cost for the provider. This provider-centric model of employment is inconsistent with the future state of the respite workforce.

Our coalition intends to find a solution. We propose to retain an attorney who specializes in not-for-profit law to explore legal alternatives to the onerous and duplicative process of agency-based worker clearance. Furthermore, we want to benchmark New York State’s worker clearance processes with those of other states, to see if we can adopt a more efficient approach that is already proven. Of course, we will engage OPWDD and its Division of Quality Improvement in the discussion so we can arrive at a workable resolution that is acceptable to state officials.

## **Solution 2: Reorienting the learning and development process for respite workers**

Just as the worker clearance process should become less agency-centric, so should the learning and development process. If the future respite worker is a part-time “gig” worker with other commitments, then the respite training program must be made as on-demand as possible.

We envision a standardized core curriculum for respite workers, utilized across the provider network in the region. The curriculum will be divided into information-transfer portions that can be effectively delivered in an on-demand online format, and skill-based portions that require in-person contact. All Region 1 providers will have a chance to offer input into the curriculum, and each agency's participation will be voluntary. Individual providers will be able to retain their existing respite training regimens – but we believe that most providers will see the wisdom of joining their efforts to those of other providers. Indeed, it is a hopeful sign that 27 providers in the region have already expressed interest in a shared online training program for respite workers.

Already, the OPWDD Region 1 regional office is working closely with a group of providers to pilot an online respite worker training program on the Google platform. These training materials are focused on the Self Direction component of OPWDD, where the worker often knows the service recipient already. Because a majority of respite cases are not self-directed at this time, we will need to build on this Google pilot with additional training resources for respite workers who do not yet know the individuals they will be supporting. We are currently investigating various online learning systems to identify which ones are most cost-effective and efficient, so that we can move to the next level of online learning.

Our goal is to offer a universal “certification” to every respite worker who successfully completes the shared training program. Ideally, that certification will follow the worker from provider to provider, making it possible to onboard workers more quickly and meet families’ needs more nimbly. Annual recertification of respite workers will be required to ensure ongoing professional development.

Along with the required training modules, we plan to create a directory of additional learning resources to help respite workers obtain knowledge that is specific to the people they support. For example, a respite worker who supports someone on the autism spectrum will be able to complete optional modules on autism spectrum disorders.

Once the learning system is developed, there will likely be two groups of end users. On one hand will be direct support professionals who are already employed by providers. Providers will buy into the learning system so their employees can use it on an ongoing basis. We believe providers will enjoy economies of scale by also using the system to train staff in other OPWDD-funded programs such as Day Habilitation.

On the other hand will be those who want to become respite workers but are not yet affiliated with any particular providers. These prospective respite workers will be able to use the learning system to become pre-qualified, then seek employment with providers or offer their services directly to individuals and families through Self Direction. The participation of these workers in the learning system will ideally be free and, therefore, will need to be subsidized.

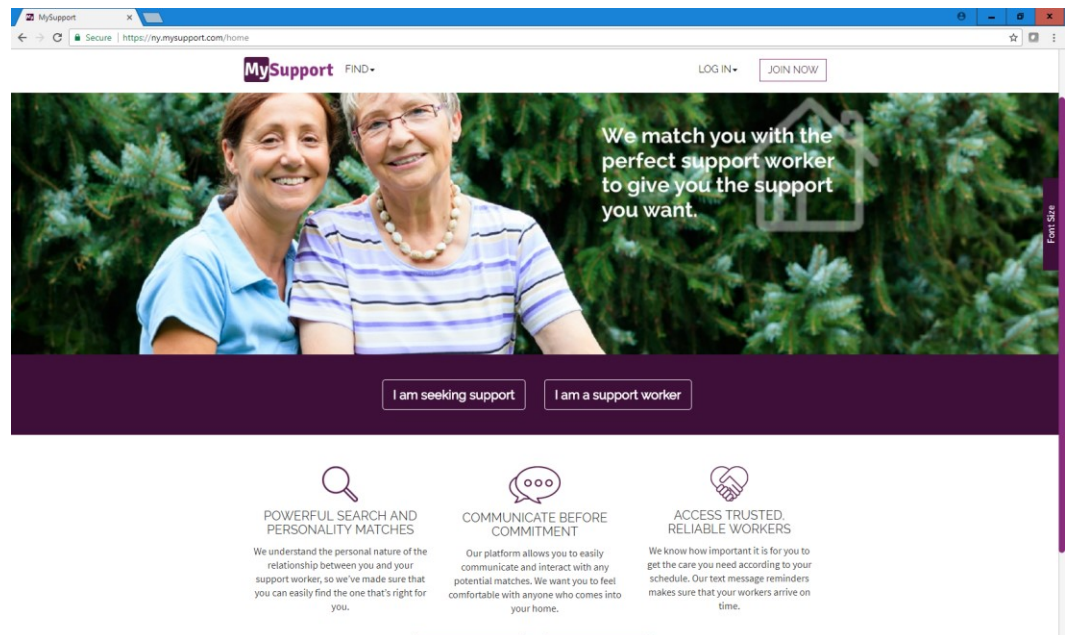
### Solution 3: Rethinking how staffing matches are made

Today, the matching of respite workers to individuals receiving services often rests on convenience and luck. A family needs respite, and a match is made based on which staff happen to be available at a particular agency. This situation is far from ideal. A lot of trust is required for family members to leave their vulnerable loved ones alone with strangers. So the matching process should be a thoughtful one, and it can be with the right tools.

An online matching system called MySupport.com gathers information about the worker and the individual, and suggests matches based on a sophisticated algorithm. Personal interests and values, demographic preferences, and location are all taken into account, resulting in a values-based compatibility that increase the likelihood of a long-term engagement. And the process is truly person-centered, because it is driven by the wants and needs of the individual and the family, rather than the preferences of providers.

Also, MySupport.com includes information about certifications and training that the worker has completed – so completion of the learning and development program outlined above would become part of the worker’s MySupport.com profile.

MySupport.com’s founder, Ari Ne’eman, is a nationally recognized leader advocate for people on the autism spectrum. He was appointed by President Barack Obama and confirmed unanimously by the United States Senate for membership on the National Council on Disability, where he served for five years.



We are looking for funding for a three-year pilot, in which we will aim to gradually scale up MySupport.com, ultimately to include 1,000 respite users and 3,000 respite workers in our region by 2022.<sup>17</sup> Our plan is to integrate MySupport.com’s functionality into a locally operated site called InTheDriversSeat.org, which already enjoys brand recognition and trust in Region 1. InTheDriversSeat.org would become the vehicle through which local families and individuals utilize the registry offered by MySupport.com. Conversations between the two organizations are already underway.

In other states, managed care organizations have been willing to fund the ongoing use of MySupport.com once its effectiveness has been established. As we prepare for OPWDD’s movement into a managed care environment in 2022, we believe the same approach can be taken here. But we cannot afford to wait for managed care organizations to enter our space before we adopt MySupport.com. Rather, we would like to dramatically expand the number of MySupport.com users, on both the supply side and the demand side, so we can reap its benefits immediately; we hope to demonstrate the effectiveness of MySupport.com now, so that we can appeal to managed care organizations to sustain it beginning in 2022.

### Inputs

Project Manager	
	\$50,000 salary plus \$15,000 fringe benefits = \$65,000 per year x 3 years = \$195,000
Workforce recruitment campaign	\$150,000
Curriculum development and deployment of online learning program	\$175,000
Research on legal alternatives to reduce duplication in onboarding	\$30,000
<u>Expansion of matching registry using online platforms</u>	<u>\$550,000</u>
<b>Total 3-Year Project Budget:</b>	<b>\$1,100,000</b>

### Outcomes

We intend to track the outcomes of this project by collecting and analyzing the following data points at the end of each of the three years:

- Respite worker vacancy and turnover rates: We anticipate that vacancy and turnover rates will decrease among respite workers in Region 1 due to more effective recruitment efforts, improved onboarding, a stronger learning and development program, and more compatible matches

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<sup>17</sup> Leadership of OPWDD Region 1’s regional office is proposing to OPWDD central office leadership that OPWDD contribute toward the cost as a value-based payments pilot, as part of the transition to managed care.

- Unmet need: We expect to reduce unmet need by 50% over the project period
- Time to service: We expect to reduce families' wait time for respite services, and will quantify the reduction in time from request to fulfillment
- Reliance on institutional care: Those whose immediate needs are met in the community are likelier to remain living at home; therefore, we will study the effect of how greater access to respite services helps to reduce institutionalization
- User satisfaction: Through satisfaction surveys, we will explore changes in how satisfied families and individuals are with their respite services over the three-year period
- Personal Outcome Measures: We will engage providers in a discussion about using the Personal Outcome Measures interview and tracking process to explore how an improved respite system is contributing to such POMs factors as "People experience continuity and security" (#4) and "People choose services" (#19)

## Conclusion

Thank you for the opportunity to share this strategy for reinventing the respite system in OPWDD Region 1. We are excited to work with you to build a better respite system that benefits individuals, families, workers, providers and taxpayers alike.