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Office for People With Developmental Disabilities

Report to the Legislature

Residential Request List

February 2016

Report to the Legislature, February 2016
Office for People With Developmental Disabilities
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Executive Summary

The Office for People With Developmental Disabilities (OPWDD), as it seeks to evolve its housing strategies to better respond to demand and changing models of support that can be more tailored to the individual, has heard concerns from many individuals and families who fear that they will be unable to access residential supports when they are needed or plan a future for their loved one. More specifically, individuals and families have expressed concern over how long they will need to wait for a residential service and what options will be available to them.

To assist in meeting residential service needs and to further its housing planning process, OPWDD undertook an unprecedented attempt to reach the more than 11,000 individuals reflected on the Residential Request List (RRL) who had at some time in their history with OPWDD indicated interest in residential supports.

This outreach revealed several key findings:

- While over 60% of those contacted were interested in a traditional agency-staffed residence, a significant number were interested in pursuing non-traditional options and enhanced at-home services to keep their loved one at home longer;
- While caregiver age and length of time on the RRL do not always indicate urgency of need, these are nevertheless important factors that indicate the need for an enhanced planning process with such families to ensure that a person-centered plan can be implemented to meet each person's residential needs; and

- Higher behavioral health support needs are often a more important factor in determining the urgency of placement needs than the intensity level of direct support needs. Providing enhanced assistance for families with loved ones with behavioral support needs is critical.

Based upon this outreach, and other work with individuals, families, advocates, and providers, OPWDD will continue to develop strategies to address the need for safe, accessible, affordable and individualized housing supports for people with developmental disabilities.

As described in this report and informed by its RRL outreach, OPWDD will continue to:

- Work to ensure that sufficient certified residential opportunities are available to those who need and want that level of support based on a person-centered planning process, including those living at home with aging caregivers;
- Invest in additional certified residential opportunities as warranted;
- Work to increase access to non-certified housing options to meet the needs of individuals who want and can benefit from non-certified housing; and
- Work to increase respite, day service and crisis support to help individuals and family caregivers assist those who want to live at home longer.

As described in the sections that follow, OPWDD's outreach to and collaboration with individuals, families, advocates and providers have driven the development of these strategies and will continue to do so in the coming year.

I. Residential Request List Outreach

OPWDD tracks information on individuals whose families have expressed an interest in residential supports for their family member. This information on people's requests is reflected on the Residential Request List (RRL). RRL information comes from individuals and caregivers who request residential services. However, the RRL does not contain information regarding individuals' needs for specific types of housing. Some people were added to the list as children, in anticipation of future residential need. In early 2015, the RRL contained the names of approximately 11,000 individuals who had indicated an interest in residential supports.

In 2015, in collaboration with its stakeholders, OPWDD undertook a review of the requests for residential services reflected on the RRL. This review was conducted in response to concerns raised by individuals, families, advocates, and providers regarding the number of individuals on the RRL; to update information provided in the past about residential service needs and identify immediate needs that must be met; and to gain a better understanding of the long-term needs of people on the RRL. After designing the RRL survey instrument and outreach process, OPWDD contracted with the Human Services Call Center (HSCC) operated by the Office for Children and Family Services (OCFS) to conduct the surveys via telephone.

OPWDD conducted extensive outreach to update contact information for individuals on the RRL to ensure the accuracy of that information. OPWDD mailed over 11,000 letters between July 31, 2015 and September 15, 2015 to encourage participation in the RRL survey. An additional set of 8,000 letters were mailed in late October to people who were on the RRL but had not, at that point, completed the survey. By the end of the project, 20,788 letters were mailed out to individuals and families in order to encourage participation.

Contact information for people on the RRL was sent on a rolling basis to OCFS until October 2015, when the project was completed. Over 10,000 numbers were provided to

HSCC, and a total of 24,038 calls were made by the end of the project; families were contacted several times if necessary.

In addition to this targeted outreach, family caregivers whose loved one was not on the RRL but wanted to take the survey were able to do so. This generated an additional 613 responses.

Summary of RRL Telephone Survey Outreach

Phone Calls

- ✓ Total # of outbound calls attempted – 24,038
- ✓ Total # of inbound calls received – 3,736

Surveys (note: in some cases, multiple surveys were completed for the same person)

- ✓ # of surveys completed by caregiver for individual on the RRL – 3,622[1]
- ✓ # of surveys completed by individual on the RRL – 206
- ✓ Total # of completed surveys completed by individual or caregiver on the RRL – 3,828
- ✓ # of surveys completed by caregiver for individual not on the RRL – 613
- ✓ # of surveys completed by individual *not* on the RRL – 21
- ✓ Total # of completed surveys completed by individual or caregiver not on the RRL – 634
- ✓ Total # of completed surveys – 4,462

Responding to Immediate Needs

OPWDD maintains data on residential and other service requests, and regularly learns about the needs of individuals new to the system who come to the Front Door. Furthermore, if an RRL survey respondent selected a response while being interviewed

[1] OPWDD identified 87 instances where multiple caregiver surveys were completed for an individual– 3622 surveys were completed for 3535 people.

that indicated an individual might be experiencing a situation that would result in an immediate need for service, the individual's name and contact information were provided to the respondents' local OPWDD Regional Office for follow-up. Approximately 600 responses indicating an individual with a possible immediate need were referred to the Regional Offices to ensure these needs would be met.

II. Results of Residential Request List Outreach

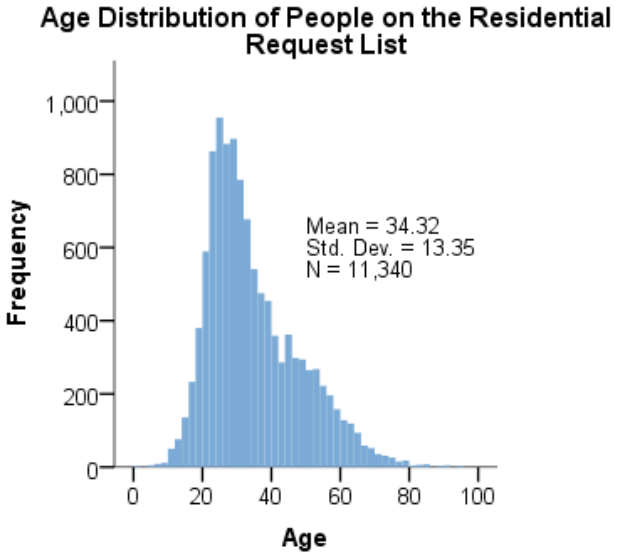
The data presented in this section highlights what was learned from OPWDD's Residential Request List outreach.

Age of People on the RRL

Average age of individuals on the RRL: 34 years old

Age range for the majority of individuals on the RRL: between 21 and 35 years old

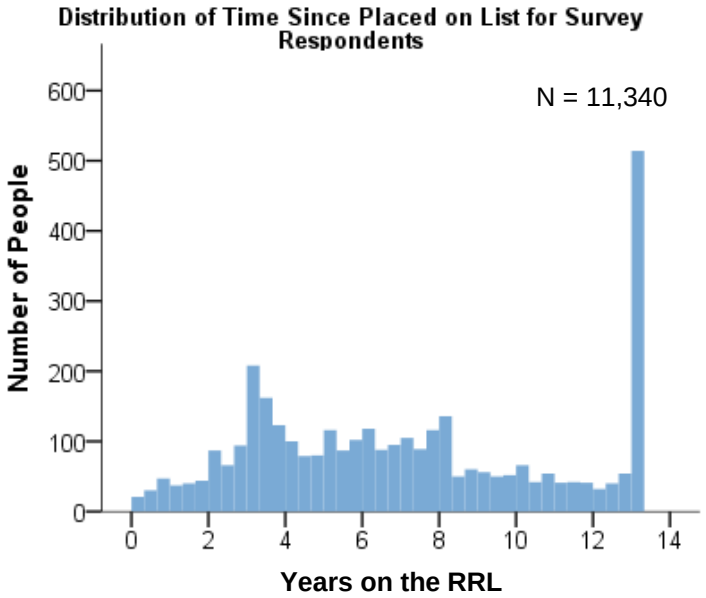
The graph to the right and table below shows the distribution of ages.



Age Categories by Region of Individuals on the RRL

		Age Category				Total
		0-17	18-22	23-39	40+	
Western/Finger Lakes	Count	194	391	1,091	463	2,139
	Percent	9.10	18.3	51.0	21.6	100.0
Central NY/Broome/Sunmount	Count	73	211	650	340	1,274
	Percent	5.7	16.6	51.0	26.7	100.0
Capital District/Taconic/Hudson Valley	Count	80	235	1,204	554	2,073
	Percent	3.9	11.3	58.1	26.7	100.0
Metro/Brooklyn/Staten Island/Hudson Valley	Count	115	322	1,830	1,195	3,462
	Percent	3.3	9.3	52.9	34.5	100.0
Long Island	Count	63	209	1,356	764	2,392
	Percent	2.6	8.7	56.7	31.9	100.0
Total	Count	525	1,368	6,131	3,316	11,340
	Percent	4.6	12.1	54.1	29.2	100.0

Time on the RRL



As noted previously, since some individuals were placed on the RRL when they were children in anticipation of future needs, the length of time on the RRL can vary widely.

Average Length of Time on the RRL: Approximately seven years

The graph to the right displays the length of time those currently on the RRL have been on the list. (Note: the large spike at the end of the distribution reflects the starting point of tracking what was formerly known as the "NYS CARES" list in OPWDD's data system in 2002.)

The RRL and New York State CARES

OPWDD's Residential Request List (RRL), formerly known as NYS CARES (Creating Alternatives in Residential Environments and Services), was launched in 1998 and served for several years as the primary initiative creating certified residential opportunities in the OPWDD system.

Over time the philosophy on which OPWDD based the development of certified residential opportunities changed as our commitment grew to supporting people in more individualized and person-controlled settings. The RRL now focuses on individuals who have expressed an unmet need for residential services in the near or more distant future, and is used primarily as a tool to help OPWDD plan for an array of residential services for which individuals and families have expressed a need.

Urgency of Need

Percentage of people on the RRL for more than 10 years who report needing a residential opportunity within two years: 24.8%

Percentage of people on the RRL for less than 10 years who report needing a residential opportunity within two years: 27.7%

Findings indicate that those on the RRL for more than ten years were not more likely to report on the survey that they desire their family member with developmental disabilities to move within two years.

Race and Ethnicity of People on the RRL

Data on race and ethnicity were collected for 10,306 of the individuals on the RRL:

Number of People in Each Region of Various Races/Ethnicities N=10,306[2]							
	Race/Ethnicity						Total
	White	African-American	Hispanic	Asian or Pacific Islander	American Indian or Alaskan	Other	
Region 1 *(Western NY, Finger Lakes)*	1,518	263	80	25	8	22	1,916
Region 2 *(Central NY, Broome, Sunmount)*	1,065	82	19	9	9	16	1,200
Region 3 *(Capital District, Taconic, Hudson Valley)*	1,424	245	113	35	0	24	1,841
Region 4 *(New York City)*	1,039	1,061	715	207	3	93	3,118
Region 5 *(Long Island)*	1,697	273	165	50	3	43	2,231
Statewide Total	6,743	1,924	1,092	326	23	198	10,306

[2] Data on race/ethnicity was available for 10,306 individuals out of the 11,340 on the RRL.

Services People Receive Now

According to OPWDD's tracking and billing system, over 87% of the individuals on the RRL are enrolled to receive at least one OPWDD service (9,911 people). Of the 87% who are enrolled in at least one service:

88% (8,696 people) are enrolled in service coordination – a service that helps connect people to services they need and want

61% (6,054 people) are enrolled in day services – services that help people learn new skills

60% (5,917 people) are enrolled in family support services – services that give families a break from caregiving when needed

Family Caregivers' Service Needs

The RRL survey revealed a great deal about the responsibilities of family caregivers:

48.2% of caregivers reported that their family members on the RRL need help with almost all basic activities

53.5% of caregivers reported that there is only one caregiver providing care to the individual

86.3% of caregivers reported that they, the parents, help their family member the most

61.4% of caregivers reported they themselves are experiencing issues (health, stress-related or other) that make it hard to provide care

46.0% of caregivers reported being over the age of 60

Caregivers were also surveyed about their ability to obtain the services they need to support their family member living at home:

35.5% of caregivers reported that they didn't have enough services to meet their family members' needs at home	**60.7%** of caregivers said that more services would help the person stay at home longer	**53.4%** of caregivers requested more respite services and **54.4%** of caregivers requested more day services to help their family member stay at home longer

Preferred Housing of Caregivers

Caregivers were asked about what they thought the preferred housing arrangement would be for their loved ones currently living at home. In addition to stating different forms of housing, caregivers also responded that it was their preference for their loved one to stay at home longer with additional support:

60.7% of caregivers said that they would like their family member to remain living at home if they had more services	**Over 90%** of respondents are interested in learning about residential options other than those that provide 24/7 staffing support	**37.4%** of caregivers were uncertain what a good time for the individual to move would be **16.9%** reported that "within two years" would be a good time for their family member to move

Family caregivers indicated the type of housing they would prefer for their family member:

62.0% reported preferring a residential setting where services and supports are provided by an agency

32.8% of caregivers reported that owning or renting a home where needed supports and services would be available was desired for their family members

5.2% reported wanting something other than the options presented

The table below indicates these requests, by region:

Number of People in Each Region Desiring Various Housing Options N=2,976[3]

	Type of Housing Desired				Total
	Own or rent and live by yourself with services	Own or rent and share services with others	Live in a house or apartment staffed by an agency (group home)	Other	
Region 1 *(Western NY, Finger Lakes)*	69	85	365	31	550
Region 2 *(Central NY, Broome, Sunmount)*	49	77	177	14	317
Region 3 *(Capital District, Taconic, Hudson Valley)*	78	104	307	30	519
Region 4 *(New York City)*	127	146	500	37	810
Region 5 *(Long Island)*	93	137	509	41	780
Statewide Total	416	549	1,858	153	2,976

[3] 2,976 of the 4,462 total survey respondents responded to this question on the RRL survey.

Intensity of Individual Needs

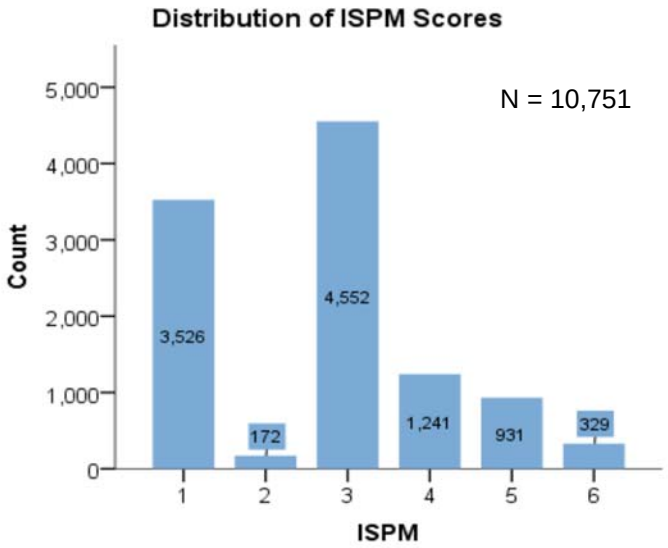
Individuals reflected on the RRL have diverse behavioral health and direct support needs. To measure these needs, OPWDD uses the Individual Services Planning Model (ISPM). The ISPM produces a score which combines a variety of information about a person's ability for self-care, their overall health, and any behavioral health needs they have. Ability and health are captured in the "direct support score," which is considered along with the "behavior score" to result in an ISPM score.

There are six different ISPM scores. Individuals with odd-numbered ISPM scores of one, three or five all have low behavioral health support needs. A score of one indicates that they also have low direct support needs. A score of three indicates they have moderate direct support needs, and a score of five indicates high direct support needs along with few or no behavioral health support needs. Individuals with an even-numbered ISPM score of two, four or six all have high behavioral health support needs. A score of two indicates low direct support needs; four indicates moderate direct support needs; and six indicates high direct support needs along with high behavioral health support needs.

The table below summarizes how to interpret an ISPM score:

Interpreting ISPM scores	
ISPM Components	ISPM Score
Low direct support score/Low behavior score	1
Low direct support score/High behavior score	2
Medium direct support score/Low behavior score	3
Medium direct support score/High behavior score	4
High direct support score/Low behavior score	5
High direct support score/High behavior score	6

The graph to the right contains the distribution of all known ISPM scores for individuals on the RRL[4]. The vast majority of individuals on the RRL have an ISPM score of either one or three. (This is not a unique characteristic of the RRL, as over half of the individuals in OPWDD's service system have an ISPM score of one or three.)



The table below displays the number of people on the RRL with a particular ISPM score, by region:

Number of People in Each Region with Various ISPM Scores							N=10,751
	ISPM Score						Total
	1	2	3	4	5	6	
Region 1 *(Western NY, Finger Lakes)*	751	43	826	232	195	61	2,108
Region 2 *(Central NY, Broome, Sunmount)*	438	19	519	159	75	39	1,249
Region 3 *(Capital District, Taconic, Hudson Valley)*	677	33	739	252	144	68	1,913
Region 4 *(New York City)*	863	43	1495	358	315	108	3,182
Region 5 *(Long Island)*	797	34	973	240	202	53	2,299
Statewide Total	3,526	172	4552	1241	931	329	10,751

The majority of all individuals on the RRL have similar characteristics to the overall population served by OPWDD in terms of age and ISPM scores and are currently connected to OPWDD services and supports.

[4] ISPM data is derived from the Developmental Disabilities Profile (DDP). A DDP is only completed for an individual who is enrolled in a particular service. Since not everyone on the RRL is receiving (or had received at some point) services which require the completion of a DDP, ISPM data is not available for all 11,340 people on the RRL. The above graph reflects the data available, which reflects the ISPM scores of 10,751 people on the RRL.

The data in the table below provides information about the intensity of service needs. ISPMs of one and three are considered to reflect lower need, and 75% of those on the RRL have ISPM scores of one or three. In the overall system, 60% of those receiving services have ISPM scores of one or three. This means that 40% of people in the overall system are considered to have more intensive needs (an ISPM score of 2, 4, 5 or 6) while 25% of people on the RRL are considered to have more intensive needs.

How ISPM Scores Compare:
All 130,000 People Served By OPWDD and Those On the RRL

	All 130,000 Served	Those on the RRL
ISPM 1 (Low Dir/Low Behav)	20%	33%
ISPM 2 (Low Dir/High Behav)	1%	2%
ISPM 3 (Med Dir/Low Behav)	40%	42%
ISPM 4 (Med Dir/High Behav)	19%	11%
ISPM 5 (High Dir/Low Behav)	12%	9%
ISPM 6 (High Dir/High Behav)	8%	3%

The relationship between ISPM scores and caregiver responses to a question about having enough services was also analyzed. Caregivers supporting individuals with behavioral health support needs were more likely to report the need for more in-home services compared to other caregivers. Over 43% of caregivers supporting individuals with an ISPM score of 2 (who have low direct support needs but also have behavioral health support needs) reported they do not have enough services compared to 24% of caregivers supporting individuals with an ISPM score of 1 (who have low direct support needs but few, if any, behavioral health support needs). This pattern holds true when comparing individuals with ISPM scores of 3 and 4, as well as 5 and 6. Even numbered ISPM scores indicate higher behavioral health support needs.

The Impact of Behavioral Health Support Needs

The information collected in the RRL survey suggests that the urgency of need for placement has more to do with the particular characteristics of an individual, specifically

behavioral health support needs, than the amount of time an individual has been on the RRL. OPWDD examined the relationship between ISPM scores and the desired timeframe for a residential setting alternative.

As noted before, individuals with behavioral health support needs have ISPM scores that end with an even number (i.e. 2, 4 or 6.) Nearly double the percentage of family members caring for individuals with an ISPM score of 2 would like a residential opportunity in the near future (45.2%), compared to those caring for individuals with an ISPM score of 1 (23.6%). This same pattern holds when comparing individuals with ISPM scores of 3 and 4, as well as 5 and 6. This pattern indicates that caring for individuals at home with challenging behaviors is linked to a more urgent need for residential placement.

Relationship between ISPM and Desired Timeframe for Residential Setting N=1,994[5]					
		Within 2 years		More than 2 years	
		Frequency	Percent	Frequency	Percent
ISPM	1	122	23.6	394	76.4
	2	14	45.2	17	54.8
	3	215	24.1	677	75.9
	4	108	35.6	195	64.4
	5	50	28.1	128	71.9
	6	26	35.1	48	64.9
Total		535		1,459	

Interest in Housing Alternatives

RRL survey data shows that a sizable proportion of individuals are interested in living alternatives other than group homes and traditional OPWDD-certified settings:

[5] 1,994 of the 4,462 total survey respondents responded to this question on the RRL survey and had ISPM data on record for use in this comparison.

Type of Housing Desired		N=3,043[6]
	Frequency	Percent
Live in own home or apartment with in-home services	433	14.2
Live in home or apartment shared with others with in-home services	566	18.6
Live in a house or apartment staffed by a provider agency	1,887	62.0
Other	157	5.2
Total	3,043	100.0

A majority (62%) of those surveyed indicated interest in a traditional, agency-staffed certified model, and OPWDD will continue investments in new certified development to meet this need. A third of the respondents indicated interest in more individualized, non-certified options. ISPM data indicating that 75% of people on the RRL have a low or moderate need for direct supports coupled with low behavioral health support needs (ISPM 1 or 3) suggests that, for those who want more independent living, this desire for more independent living is both realistic and achievable.

Offers of Residential Services

RRL data shows that more older caregivers (age 60+ years) than younger caregivers were offered the opportunity at some point in the past to have their family member move to a group home or apartment staffed by an agency. 23% of older caregivers surveyed reported they received an offer for residential services and declined the opportunity, indicating non-urgent need or dissatisfaction with the option offered.

[6] 3,043 of the 4,462 total survey respondents responded to this question on the RRL survey.

Whether a Person Was Offered A Chance to Move			N=3,105[7]	
	Older Caregivers		Younger Caregivers	
	Frequency	Percent	Frequency	Percent
No	1093	76.6	1448	86.2
Yes	333	23.3	231	13.8
Total	1426	100	1679	100

Other Supports and Services

Another goal of the RRL outreach was to evaluate caregivers' needs for in-home services to continue to support their family members. As noted earlier, 60.7% of caregivers said that they would like their family member to remain living at home if they had more services. Survey respondents also were asked specifically if respite and day supports may help an individual with developmental disabilities to live at home longer.

Respite is scheduled relief for caregivers, and day supports provide activities during the day for people with developmental disabilities. A large majority (70.2%) of caregivers thought that additional respite services may help keep their family member with developmental disabilities home longer. Survey respondents were asked whether day services would be an option to help an individual with developmental disabilities live at home longer, and 67% indicated that they thought additional day services may help their family member be cared for at home longer. Through the RRL survey, 53.4% of caregivers requested more respite and 54.4% of caregivers requested more day services to help their family member stay at home longer.

[7] 3,105 of the 4,462 total survey respondents responded to this question on the RRL survey.

III. Residential Support: Supply and Demand in the OPWDD System

One of the pressing questions that OPWDD faces is whether the service system has sufficient capacity to meet the needs of individuals seeking a residential service. Demand for housing includes people who need an opportunity in a residence immediately and those supported at home who may need an opportunity in the future.

OPWDD's available supply of residential opportunities for a given year is comprised of vacancies in existing capacity, and opportunities created through the development of new capacity. Based on 2015-16 trends, it is projected that 1,421 certified residential opportunities in the existing system will become available in fiscal year 2016-17. In 2016-17, an additional 302 opportunities for rental subsidies are anticipated to become available, based on historical usage trends[8]. Thus, the total residential capacity in the existing system anticipated to become available is 1,723 housing opportunities for 2016-17.

Identifying Priority One Demand[9]

In the analysis which follows, demand estimates include people projected to have a priority one status for needing residential services. In addition, remaining projected capacity is identified as able to serve additional individuals with a priority two or three status.

[8] One recommendation of the Transformation Panel is to review rental subsidy amounts; implementation of this recommendation could impact the number of subsidies.
[9] The priority levels range from most immediate need (priority 1) to less immediate levels of need (priorities 2 and 3.) For more information, search for "certified residential opportunities protocol" using the search feature at the top of OPWDD's homepage (www.opwdd.ny.gov)

Potential Number of Priority One People Seeking OPWDD Housing	2016-17 Projections
Estimated Housing Supply Before New Investments	
Available Opportunities	**1,723**
Anticipated Certified Vacancies	1,421
Anticipated Rental Subsidies	302
Estimated Housing Demand	
Requested or Needed Service (Housing Demand, Priority One)	**1,711**

The analysis of supply and demand shows that OPWDD has the existing resources needed to meet the anticipated residential needs of individuals identified as priority one. OPWDD recognizes that matching an individual to an available opportunity must be done in a person-centered way and, at times, an available opportunity may not be appropriate for an individual. In these instances, OPWDD's Regional Offices are authorized to develop new capacity to meet these needs.

The Governor's Executive Budget proposes $120 million in new resources to assist in meeting the needs of individuals living at home with caregivers and those who are transitioning from the school system. A majority of this new funding will be allocated specifically to meet the needs of those living at home, including $10 million that will be made available for priority two and priority three individuals in need of residential supports.

Identifying Potential Demand: Priority Two and Three Individuals

Data from the RRL survey was used to estimate the potential need for residential services for individuals with a priority two or three status and increasing support needs. Reflected in this analysis were priority two individuals with an aging caregiver and/or a caregiver experiencing health and stress related issues that could make it difficult to continue providing care. In the table, *"short-term need"* is defined as the potential need

of caregivers who state they have health or stress-related challenges; state a need for housing in the next two years; and, where the individual they are caring for has an ISPM score that is not one or three (indicating higher behavioral health and/or direct support needs.)

For each of the various categories in the table below, the number of respondents from the survey was projected to reflect the total number of people on the RRL who may fall into one of those categories:

Potential Number of People With a Short-Term Need For Housing[10]	
Individual living with caregiver (age 81+) and short-term need	9[11]
Individual living with caregiver (age 71-80) and short-term need	39[12]
Individual living with caregiver (age 61-70) and short-term need	206[13]
Individual living with caregiver (age 61 or older) having health or stress-related challenges and wanting group home (timing of need undetermined)	198[14]

Of the caregivers surveyed in arriving at the above projections for those 61 and over with short term need, 56 of 59 were currently receiving Medicaid Service Coordination. Individual plans of care are created through this service, indicating the vast majority of those on the RRL are also receiving support necessary to plan for accessing a residential service.

As the table shows, there is projected need which may lead to requests for additional housing-related services. The two largest groups of projected potential need are among

[10] Counts in this table reflect individuals *not* known to be working with Regional Office staff to meet emergent need(s).
[11] This projection was extrapolated from results of the RRL survey, whereby 2 respondents indicated responses that satisfied the criteria regarding short-term need for housing services noted above.
[12] This projection was extrapolated from results of the RRL survey, whereby 9 respondents indicated responses that satisfied the criteria regarding short-term need for housing services noted above.
[13] This projection was extrapolated from results of the RRL survey, whereby 48 respondents indicated responses that satisfied the criteria regarding short-term need for housing services noted above.
[14] This projection was extrapolated from results of the RRL survey, whereby 46 respondents indicated responses that satisfied the criteria regarding short-term need for housing services noted above.

individuals living with a caregiver between 61-70 and who have a short term need (as previously defined), and those caregivers who identified they are experiencing health or stress related issues and who requested residential services for their loved one at any time in the future. The table does not reflect all priority two and three requests. OPWDD is actively working with 1,386 people of priority two or three status to identify residential opportunities for these individuals.

As was previously noted, the Governor's Executive Budget proposes $120 million in new resources to assist in meeting the needs of individuals living at home with caregivers and those who are aging out of the school system. A majority of this funding will be allocated specifically to meet the needs of those living at home. In addition, $10 million of this new funding will be made available to the Regional Offices for development of residential opportunities for people with priority two and three status.

Regional stakeholder groups will be created to help identify local needs in prioritizing use of these funds for priority two and three individuals. This will include assisting in OPWDD's review of how to best target resources for those priority two and three caregivers in most immediate need and in planning for those whose needs may be longer term. OPWDD is instructing its Regional Offices to focus attention on those identified during the RRL outreach as having an aging caregiver and not having been offered a placement, as well as those not on the RRL having an aging caregiver and short term need for residential supports (within two years), and other situations in which the provision of ongoing care is causing issues for the caregiver.

IV. Strategies for Achieving Housing Goals

Based upon the Residential Request List outreach, and continued stakeholder engagement over the past year, OPWDD developed a set of strategies to increase the availability of housing to serve individuals with developmental disabilities. These strategies were also informed by the recommendations of the Transformation Panel, which provide a vision for flexible and responsive housing supports across the spectrum of individuals' needs, as well as data from OPWDD's Front Door. The five specific strategies OPWDD will pursue as a result of the RRL outreach project are detailed in the following section, but can be summarized as follows:

1. OPWDD must continue to focus on the housing needs of those needing immediate support;
2. At the same time, OPWDD must adequately plan for and begin to meet the needs of individuals not identified as priority one, as they become more urgent;
3. OPWDD must continue to expand the availability of housing supports through maximizing existing capacity and engaging in investments as needed;
4. OPWDD must increase its support for noncertified residential alternatives to provide opportunities outside of traditional certified settings; and
5. OPWDD must increase opportunities for respite, day service and crisis support to enable individuals to continue living in their family homes.

Meeting Housing Needs of Those Seeking Immediate Support

The most critical priority for OPWDD is to meet the immediate housing needs of individuals and families in crisis. When individuals request a certified opportunity, OPWDD Regional Office staff work with families, individuals and provider agencies to secure an opportunity that will best meet the individual's needs and preferences.

In May of 2015, OPWDD implemented the Certified Residential Opportunities (CRO) protocol to provide direction and create consistency in the management of certified

housing opportunities. The CRO process is one tool used to assess overall need for certified residential services and inform the need for new residential service capacity in the system. The CRO protocol is designed to ensure timely response to urgent needs; to understand and address the unique needs of each individual; and to apply consistent, statewide standards that allow equal opportunity to service access. The approach involves a collaborative effort between the individual and family, OPWDD Regional Offices, service coordinators and provider agencies. The protocol reinforces the principles of individual choice and the importance of helping individuals seek opportunities to live in the community in the least restrictive environment possible.

The CRO protocol uses a system of priority level determinations[15] based on individual circumstances. Individuals seeking certified residential opportunities are designated a priority one, two or three status. This designation occurs when an individual identifies a need for a certified residential opportunity to OPWDD's Front Door. The amount of time someone is on the CRO does not impact their priority status.

Expanding Availability of Housing Supports

New York State is among the top states in the nation in the provision of residential services to individuals with developmental disabilities. On a per capita (per state resident) basis, New York spends more on residential services and community supportive services than any state in the nation.[16] OPWDD provides supports to over 130,000 New Yorkers with developmental disabilities. Nearly 41,000 individuals receive residential supports, with approximately 38,000 individuals receiving services in certified group residences and another 2,800 receiving rental subsidies. For individuals not receiving residential supports, other services, including in-home supports and caregiver relief services, assist individuals in residing with their families or other caregivers.

[15] The priority levels range from most immediate need (priority 1) to less immediate levels of need (priorities 2 and 3.) For more information, search for "certified residential opportunities protocol" using the search feature at the top of OPWDD's homepage (www.opwdd.ny.gov)

[16] Institute on Community Integration (UCEDD), University of Minnesota: National Residential Information Systems Project, 2014.

Approximately $65 million in Balancing Incentive Program (BIP) transformation grants were awarded to over 100 organizations and agencies in 2015 to develop systematic improvements to service delivery systems, enhance community integration, design approaches for serving individuals with complex needs in the community, and increase employment opportunities for individuals with developmental disabilities. Eighteen of these BIP grants, representing nearly $10 million in funding, are focused on housing and family care programs.

In addition, Governor Cuomo's 2016-17 Executive Budget proposes an additional $120 million of new service dollars to support individuals and their families. Of the $120 million in new funding proposed in the 2016-2017 budget, a majority will be allocated to specifically meet the needs of those living at home regardless of priority category. In addition, a total of $10 million of that $120 million in new resources will be made available through OPWDD's Regional Offices to meet the residential needs of priority two and three individuals. This funding is specifically dedicated to provide access for people living at home to certified residential opportunities and non-certified residential opportunities across the state. Local groups of stakeholders, individuals, parents and advocates will be established to help inform how these resources are used.

Finally, based on the recommendations of the Transformation Panel, we are reviewing the prioritization criteria which are used in determining the allocation of residential services to ensure that those living at home are treated equitably, with particular focus on serving individuals with more significant needs.

Increasing Individual, Family and Caregiver Support

As noted in the RRL Survey findings, over 60% of respondents indicated that they would like their family member with developmental disabilities to remain living at home if they had more services. One of the most commonly requested services is respite, which provides relief to the primary caregiver.

OPWDD is taking the following steps to increase respite options:

- Working with the Department of Health (DOH) to develop a new standardized rate methodology;
- Based on recommendations of the Transformation Panel, OPWDD is engaged in regional respite focus groups to identify the need for increased respite capacity and day habilitation capacity;
- Redesigned the self-directed service option to increase opportunities for individuals to self-hire staff and to more easily schedule respite and other self-directed services; and
- Assisting those with behavioral health support needs to live successfully in the community by fully implementing the Systemic, Therapeutic, Assessment, Resources & Treatment (START) model statewide. START is a nationally recognized model that strengthens efficiencies and service outcomes for individuals with developmental disabilities and behavioral health support needs who are living in the community.

Expanding Options for Non-Certified Housing

Meeting the needs of individuals across the spectrum of housing options also requires OPWDD to expand the availability of non-certified housing options. OPWDD has actively supported the development of a variety of non-certified housing opportunities in an effort to increase the choices available to individuals who do not need or want 24/7 supports, but who also are looking to live more independently (32.8% of respondents on the RRL survey).

Since 2013, 78 people have accessed integrated affordable housing that was supported through set-asides for people with developmental disabilities. Opportunities for an additional 79 individuals are under construction. The 2016-17 Executive Budget proposal builds on these initial investments and includes an additional $15 million for the development of supportive housing opportunities to serve individuals with

developmental disabilities. Based on OPWDD's experience since 2013, this significant increase could support up to 150 new residential opportunities.

OPWDD continues to support the provision of wrap-around waiver services for individuals residing in non-certified settings, with a specific focus on Self-Directed service options. In 2015, there were over 3,000 people with newly authorized Community Habilitation services, which are provided in the community and in people's non-certified residences.

In addition to its work in developing supportive housing capacity for people with developmental disabilities, OPWDD has made a significant commitment to providing rental subsidies for those living in non-certified settings through the Individual Supports and Services (ISS) program. OPWDD supports approximately 2,800 individuals across the state through ISS. These rental subsidies increase the affordability of community housing, and can supplement other housing subsidies from the federal government. Services such as community habilitation support the ability of individuals to live in their own apartments in the community.

In 2014, OPWDD implemented a new Medicaid waiver service entitled Community Transition Services (CTS). This service offers a one-time opportunity to access up to $3,000 towards the cost of establishing an apartment for an individual moving from a certified setting into a non-certified home where the individual has control of the setting (e.g., the individual's name is on the lease). The $3,000 can be used for items such as cleaning, purchasing of furniture, linens, dishes, etc. This service is designed to remove a major barrier for individuals interested in moving out of a group home setting into their own apartments.

Finally, OPWDD continues to support and to grow its array of non-certified housing options, including options such as Live-in Caregiver for individuals who self-direct care, and Shared Living arrangements.

Evaluating System Change to Maximize Opportunities

Several changes are underway which will allow OPWDD to maximize residential capacity and make new capacity available where needed:

1) The Coordinated Assessment System, when implemented, will enable OPWDD to better assess and determine the needs of those served through the system, and inform investment in residential and at-home services.
2) Greater flexibility will result from the adoption of care management in the OPWDD system, and this greater flexibility will allow the system to be more responsive to the needs of individuals.
3) As recommended by the Transformation Panel, and in response to feedback from stakeholders requesting a review of the criteria for prioritization and consistent application of those criteria as they relate to access to residential supports, OPWDD will review the criteria for determining priority as well as the process in Regional Offices for assigning priority. The purpose of this review will be to ensure that we are using and developing capacity in a way that is most responsive to the needs of individuals and caregivers.
4) Additional recommendations from the Transformation Panel will assist in evaluating and maximizing capacity, and better targeting investments. These include an overall system review of existing certified and non-certified capacity and evaluation of individuals who may wish to leave a certified residence for a more independent residential opportunity.
5) Federal Home and Community Based settings rules require careful evaluation of individual choice in residential settings and maximizing individuals' control over their lives.

As time progresses, the greater demand we are seeing for personalized housing, individual control, and expanded in-home services are expected to shape the evolution of the OPWDD system. Both supply and demand in the system need to be carefully and

routinely evaluated to maximize resources already in the system and to develop new capacity to meet people’s needs.

Conclusion

This report has described the many ways OPWDD is committed to expanding access to home and community-based services, and offer more choice and options. In conclusion, we would first like to thank the thousands of people who participated in this process and helped to make it a success. The value of the time family caregivers took to provide crucial information through the survey process cannot be understated, nor can the commitment of resources from the Legislature to support this important work. The participation of those who attended the Transformation Panel's public forums to provide their feedback on residential services rounded out this truly collaborative process. OPWDD thanks all of these individuals for their contribution.

This report has summarized the outcomes of OPWDD's efforts to get a more detailed understanding of the residential needs of New Yorkers with developmental disabilities and put forward a plan to meet these needs now and in the future. Much of OPWDD's history is focused on providing safe, healthy and supportive homes for people with developmental disabilities in the community. This focus on the community led to the first great evolution of New York State's developmental disability service system, offering services to individuals in residential settings such as certified group homes. Through efforts spanning an entire generation, a robust capacity now exists for these kinds of residential services in New York State.

The commitment to the system we know today exists alongside increasing efforts to design new, flexible, individualized housing and alternative services and supports, such as rental subsidies. Building upon the system that exists today by expanding non-certified housing and in-home supports is an important feature of OPWDD's long-term plan to serve individuals with residential needs.

The RRL outreach project together with information from OPWDD's Front Door, the recommendations of the Transformation Panel, and the hundreds of stakeholders who provided feedback all contribute to an important step in the development of a five-year

comprehensive plan for meeting the residential needs of New Yorkers with developmental disabilities. The data gained through the RRL effort will be updated on a regular basis and will be reported to stakeholders to measure progress in meeting individuals' needs. Through these robust partnerships and collaborations, OPWDD's commitment to support individuals with developmental disabilities and their families is renewed and strengthened going forward into the future.

Appendix I: Text of RRL Survey Instrument

NYS OPWDD Residential Request List - Caregiver Survey

Individual's Name_____ Date of Birth _____
County _____

Preliminary Question: Since __(Individual's Name)'s name is on the Residential Request List, we want to check to make sure that he/she is still interested in residential services.

Please choose one (1): Yes No

If "Yes", Question 1: Can you tell me which of the following choices best describes where __(Individual's Name) lives?

Please choose one (1)

Does __(Individual's Name):

- o Live in his/her own house or apartment
- o Live in his/her parent's house or apartment
- o Live in his/her brother or sister's house or apartment
- o Live in the house or apartment of a family member other than parent, brother or sister
- o Live in the house or apartment of someone who is not family
- o Live in a nursing home or any kind of hospital
- o Live in a residential school or a school they live at
- o He/she is homeless or is living in homeless shelter right now, or is about to be homeless within the next few months
- o Live in a different setting then the options I just said

Question 2: OPWDD wants to know whether __(Individual's Name) may need help right now. We want to identify situations where we need to connect you to a Regional Office right away because of critical needs. Please answer "yes," "no" or "I don't know" to the following questions.

- o Is he/she being told by a court that he/she needs to live in a home provided by OPWDD? Yes No I don't know
- o Does he/she have a history of doing dangerous things that hurt him/herself or others? Yes No I don't know

Question 3: We'd like to know how independent __(Individual's Name) can be. Can you tell me how much help he/she needs every day? Would you say that he/she. ..

- o Needs help doing almost all basic daily activities, like staying safe, bathing getting dressed, or eating
- o Needs help doing some of the harder daily activities, like cooking or shopping
- o Needs help with just a few critical activities, like taking medication at the right time or managing finances, which means things like budgeting and paying bills on time
- o Doesn't need help with any activities most of the time
- o Are you not sure? (I don't know)

Question 4: Please answer yes or no. Does someone help __(Individual's Name) on a regular basis?

Please choose one (1): Yes No I don't know

If "Yes": Is there one person who helps him/her most of the time? Please choose one (1):

- o Individual has one caregiver that helps him/her
- o Individual has more than one caregiver that helps him/her

Question 5: From the list I am going to read, can you tell me who helps __(Individual's Name) the most, if he/she needs help? __(Individual's Name):

- o Gets most help from his/her parents
- o Gets most help from his/her brothers or sisters
- o Gets most help from his/her husband, wife or partner
- o Gets most help from his/her family other than parents, brothers or sisters
- o Gets most help from a friend who is not family
- o Gets most help from staff
- o Gets most help from someone that doesn't fit the descriptions I just said
- o I Don't Know

Question 6: (Skip if "No" or "No helper/caregiver" is the choice for Question 4)

At times, are there any issues that make it difficult to provide care for __(Individual's Name)? These issues could be health, age, stress, money, or something else.

Please choose one (1): Yes No I don't know

Question 7: (Skip if "No" or "No helper/caregiver" is the choice for Question 4)

How old is __(Individual's Name)'s primary caregiver?

- o 21 years old or younger
- o 22 – 50
- o 51 – 60
- o 61 – 70 (over)
- o 71 – 80
- o Older than 80

Question 8: How long do you think that __(Individual's Name) will be able to stay at home if he continues getting the same services that he has now? Please choose one (1)

- o Fewer than 3 months
- o Between 3-6 months
- o Between 6 months and 1 year
- o Between 1 -2 years
- o Between 2-3 years
- o Between 3-5 years
- o Between 5-10 years
- o More than 10 years from now
- o I don't know
- o Not Applicable – do not want to stay home/homeless

Question 10: Does __(Individual's Name) have enough services to meet his/her needs where he/she is now living?

Please choose one (1): Yes No I don't know Not applicable Individual does not get any services

Question 11: Would you like ___(Individual First Name) to continue to live where he/she lives now if he/she had more services?

Please choose one (1): Yes No I don't know Not applicable

Follow-up question for those who said "Yes" or "I don't know."

I am going to ask you about two kinds of services OPWDD offers that might help __(Individual's Name) live at home longer.

One type gives caregivers a break from helping the person when they need a break. The second type of services helps the person with disabilities learn new skills during the day or evening.

Let's start with the kind of service that gives caregivers a break, which some people know as "respite services." Think about your overall need for this service, including any respite services you get now.

Question: Do you think that getting respite services would help __(Individual's Name) live at home longer?
Please choose one (1): Yes No I don't know

Follow-up question for people who say "Yes, respite services would help __(Individual's Name) live at home for longer.*"* To help __(Individual's Name) live at home longer, do you think that you need respite services every day, every week, every month, or once in a while (school breaks or holidays)? Please choose one (1):

- o Daily basis
- o Weekly basis
- o Monthly basis
- o Intermittent basis (school breaks, holidays)

Note: This question is asking for the total amount of respite service the family needs, including any respite time they are currently receiving.

Follow up question for those who say they need respite on a daily basis:
About how many respite hours would be needed each day? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per day
- o Between 4 and 14 hours a day
- o More than 14 hours a day
- o I don't know

Follow up question for those who say they need respite on a weekly basis:
About how many respite hours would be needed each week? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per week
- o Between 4 and 14 hours a week
- o More than 14 hours a week
- o I don't know

Follow up question for those who say they need respite on a monthly basis:
About how many respite hours would be needed each month? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per month
- o Between 4 and 14 hours a month
- o More than 14 hours a month
- o I don't know

Follow up question for those who say they need respite on an intermittent basis:
About how many respite days would be needed each year? We're going to read you a few options. Choose the one that fits your situation.

- o Fewer than 7 days a year
- o Between 7 and 14 days a year
- o More than 14 days a year
- o I don't know

Follow-up question for those who said "Yes" or "I don't know" to "Would you like __(Individual's Name) to live with you longer if you had more services?"
Question: Now I'm going to ask about the kind of service that helps people with disabilities learn new skills and be out in the community. Do you think that getting these types of services would help __(Individual's Name) live at home for longer? Please choose *one* (1): Yes No I don't know

Follow-up for people who say "Yes" to "need help to learn new skills/be active in the community."

To help ___(Individual's Name) live at home longer, how often do you think he/she needs these services?

Please choose one (1).

- o Daily basis
- o Weekly basis
- o Monthly basis
- o Intermittent basis (school breaks, holidays)

Follow up question for those who say they need service on a daily basis:

About how many service hours would be needed each day? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per day
- o Between 4 and 14 hours per day
- o More than 14 hours per day
- o I don't know

Follow up question for those who say they need services on a weekly basis:

About how many service hours would be needed each week? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per week
- o Between 4 and 14 hours a week
- o More than 14 hours a week
- o I don't know

Follow up question for those who say they need services on a monthly basis:

About how many service hours would be needed each month? We're going to read you a few options. Choose the one that fits your situation.

- o About 4 hour or fewer per month
- o Between 4 and 14 hours a month
- o More than 14 hours a month
- o I don't know

Follow up question for those who say they need these services on an intermittent basis:

About how many service days would be needed each year? We're going to read you a few options. Choose the one that fits your situation.

- o Fewer than 7 days a year
- o Between 7 and 14 days a year
- o More than 14 days a year
- o I Don't know

Question 12: At any time in the past, has __(Individual's Name) been given a chance to move to a group home or an apartment that has agency staff available to help him/her?

Please choose one (1): Yes No I don't know

Follow–up question for those who said "yes – they were offered a chance to move:"

Did __(Individual's Name) move in to the home when it was offered to him/her?

Please choose one (1): Yes No I don't know (over)

Follow-up question for those who said "Yes, moved in to the home":

Did __(Individual's Name) stay in the home that was offered? Please choose one (1): Yes No

Follow-up question for those who said "No": The following statements are possible reasons that ___(Individual's Name) did not stay in the home offered. Please say "Yes" or "No" to the following statements as I read them if it is a reason why he/she did not stay there.

- The location was too far from the rest of the family.
  Yes No
- The location and/or neighborhood was undesirable.
  Yes No
- The home was not in good condition.
  Yes No
- __(Individual's Name) was not compatible with other people living in the house.
  Yes No
- He/she did not have his/her own bedroom.
  Yes No
- He/she did not get along with the staff at the house.
  Yes No
- __(Individual's Name)'s family lacked confidence in the agency or the staff.
  Yes No
- He/she lost his/her place in the home because of a hospitalization (either medical or psychiatric).
  Yes No
- Lack of transportation to his/her job or activity
  Yes No
- The agency requested that he/she leave the home
  Yes No
- The move to the home resulted from poor person centered planning
  Yes No
- The person did not stay for other reasons
  Yes No

Follow – up question for those who said "No, did not move in to the home":
The following statements are possible reasons that __(Individual's Name) did not move into the home that was offered. Please say "Yes" or "No" to the following statements as I read them if it is a reason why he/she did not move.

- The location was too far from the rest of the family.
  Yes No
- The location and/or neighborhood was not desirable.
  Yes No
- The home was not in good condition.
  Yes No
- __(Individual's Name) was not compatible with other people living in the house.
  Yes No
- He/she did not have his/her own bedroom.
  Yes No
- He/she did not get along with the staff at the house.
  Yes No
- __(Individual's Name)'s family lacked confidence in the agency or the staff.
  Yes No

- He/she lost his/her place in the home because of a hospitalization (either medical or psychiatric).
  Yes No
- Lack of transportation to his/her job or activity.
  Yes No
- The agency withdrew the offer to move.
  Yes No
- Financial reasons?
  Yes No
- The move to the home resulted from poor person centered planning.
  Yes No
- He/she did not move for other reasons.
  Yes No

Question 13: When it is time for __(Individual's Name) to move to a new home, what kind of home do you think he/she would like? Please choose one (1):

- o Living by herself/himself in a home she/he owns or rents getting the services she/he needs
- o Living with other people in a home they own or rent getting the services she/he needs
- o Living with other people who have a developmental disability in a home that is owned and staffed by an agency. (Agent note: This is sometimes called a group home.)
- o Other
- o I don't know/Not Applicable

Question 14: OPWDD will be developing residential options other than group homes. When the options are available, would you be interested in hearing about them?
(Agent note: other options include: housing subsidies to help people pay rent or mortgages, different kinds of shared living options where individuals rent or buy house or apartment with other people with developmental disabilities and may share staff, or other options that are being developed.)
Please choose one (1): Yes No I don't know